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Advances in Elder Abuse Research

Practice, Legislation and Policy

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Editor

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In memory of my mother,
Frances Phelan

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This book has been a journey of discovery. I am fortunate to have colleagues who agreed to write illuminating chapters within their expert areas. This has allowed me to present readers with a full account of the current knowledge, practice, legislative, and policy in the area of elder abuse and safeguarding. For this, I am truly grateful.

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Contents

Abbreviations

ACA	Affordable Care Act
ACL	Administration for Community Living
ADL	Activities of Daily Living
AEA	Action on Elder Abuse
AGSS	Abrams Geriatric Self-Neglect Scale
AoA	Administration on Aging
APS	Adult Protective Services
CBS	Central Bureau of Statistics
CHAP	Chicago Health and Aging Project
CIS	Commonwealth of Independent States
CPHNA	Community Profile and Health Needs Assessment
DH	Department of Health
DOJ	Department of Justice
DSM	Diagnostic and Statistical Manual
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
EJA	Elder Justice Act
EJCC	Elder Justice Coordinating Council
EJI	Elder Justice Initiative
ESNA	Elder Self-Neglect Assessment
EU	European Union
FA	Financial Abuse
FAST	Financial Abuse Specialist Team
GAO	Government Accountability Office
GP	General Practitioner
HHS	Health and Human Services
HSE	Health Service Executive
HIC	High-Income Country
HIQA	Health Information and Quality Authority
HMO	Community Health Clinic
INPEA	International Network for the Prevention of Elder Abuse
IPV	Intimate Partner Violence

LGBT	Lesbian, Gay, Bisexual, and Transgender
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer
LGBTQ2SIA+	Lesbian, Gay, Bisexual, Transgender, Questioning/Queer, Two-Spirit, Intersex, Asexual
LMIC	Low- to Middle-Income Countries
LTC	Long-Term Care
LTCO	Long-Term Care Ombudsman
MIPAA	Madrid International Plan of Action on Ageing
NASOP	National Association of State Long-Term Care Ombudsman Programs
NCEA	National Center on Elder Abuse
NEAIS	National Elder Abuse Incidence Study
NICE	National Initiative for the Care of the Elderly
OAA	Older Americans Act
OAFEM	Older Adult Financial Exploitation Measure
OAS	Organization of American States
OBRA	Omnibus Budget Reconciliation Act
OVW	Office on Violence Against Women
PPHF	Prevention and Public Health Fund
PHN	Public Health Nurse
PTSD	Posttraumatic Stress Disorder
Quirk-e	The Queer Imaging & Riting Kollective for Elders
ROI	Republic of Ireland
RRA	Resident-to-Resident Aggression
RSA	Resident-to-Staff Aggression
SDG	Sustainable Development Goals
SN	Self-Neglect
SN-37	Self-Neglect Assessment Measurement
SNSS	Self-Neglect Severity Score
SSBG	Social Services Block Grant
UK	United Kingdom
US	United States
USA	United States of America
UN	United Nations
UNDHR	United Nations Declaration on Human Rights
CRPD	Convention on the Rights of Persons with Disabilities
VAWA	Violence Against Women Act
VOCA	Victims of Crime Act
WHCoA	White House Conference on Aging
WHO	World Health Organization
yfAC	Youth for a Change

Chapter 1
Introduction

Amanda Phelan

The genesis of this book began in an appreciation of how practice, legislation, policy and research have expanded in relation to the topic of elder abuse. Elder abuse permeates all nations and prevalence statistics suggest one in six older people is affected by some form of elder abuse with family members representing a high proportion of abuse perpetrators (Yon et al. 2017). The growing volume of knowledge on this topic has been in tandem with the increasing responsibility of the state in the private domains of family, elder abuse being targeted as a public health issue and the construction of elder abuse under the lens of human rights. An aging global population presents a changing demographic landscape which not only requires but demands reform in how populations live, are cared for and are responded to in society. What is apparent is that safeguarding responses demand approaches that are enmeshed in an ecological model, which acknowledges the intersectionality of marginalization; this means the relinquishing of siloed contexts to older person safeguarding and the authentic embracing of systems' level prevention and intervention approaches.

1.1 Elder Abuse

Interpersonal violence is very common in contemporary society. There are many different forms which include child welfare and protection, domestic violence (intimate partner violence) and elder abuse. Other forms of interpersonal violence and abuse include bullying, homicide, genocide, human trafficking and consequences of forced displacement of populations (Ataullahjan et al. 2019).

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In this book, we concentrate on the domain of elder abuse. Elder abuse was first formally identified in the domain of medicine (Baker 1975; Burston 1975) but instances of what we would now describe as the maltreatment of older people are evident in the Bible, literature (Shakespeare's King Lear is a classic example) as well as various cultural and legislative practices (Phelan 2013). Early conceptualizations of elder abuse focused on physical abuse, while further scholarship expanded understandings to include psychological abuse, financial/material abuse, neglect, and sexual abuse. As discussed earlier, prevalence studies demonstrate that elder abuse is a global phenomenon which is impacted by issues such as culture, gender and societal recognition. National prevalence studies in community settings also indicate a wide variation rate from 2.2% in Ireland (Naughton et al. 2010) to 61.1% in Croatia (Ajdukovic et al. 2009) with a pooled prevalence from international studies of 15.7% (Yon et al. 2017). The most common form of abuse in Yon et al.'s (2017) systematic review and meta-analysis of 52 prevalence studies was psychological abuse (11.65%), with financial abuse at 6.8%, neglect at 4.8%, physical abuse at 2.65% and sexual abuse at 0.9%. The most common perpetrator in the community setting is a family member, with a shared living accommodation being a risk factor (WHO 2018). Other risk factors include the older person having a physical or cognitive dependency. For example, studies on elder abuse related to older people living with dementia show a significantly higher prevalence of abuse in both community settings and institutional settings (Fang and Yan 2018). However, any general prevalence figures are likely to be impressionistic estimates (Bonnie and Wallace 2003) and represent the iceberg theory, where we are only seeing a partial representation of true figures (Phelan 2013). Some research has also been undertaken to examine elder abuse in long-term care settings. In a 2018 systematic review involving nine studies, psychological abuse was found to the most common form of abuse (33.4%), with physical abuse at 14.1%, financial abuse at 13.8%, neglect at 11.6% and sexual abuse at 1.9% (Yon et al. 2018).

Another area of growing elder abuse scholarship relates to fraud and scams. These types of abuse range from those acts perpetrated by known individuals (family/friends) to those perpetrated by strangers. Financial abuse is particularly significant and is likely to be grossly underestimated. While family and 'known' individuals may apply strategies to have assets transferred through face to face interaction, with the advent of a technological age, more sophisticated and targeted methods have been applied to financially exploit older people. For example, one systematic review and meta-analysis estimated that 1 in 18 cognitively intact older people living in the community may be affected by scams (Burnes et al. 2017). This includes the use of direct contact through the post, the telephone, social media (Facebook, Twitter, Skype), phishing (email) or smishing (text). Such opportunistic approaches by scammers are often based on the promise of a lottery win, the potential of a relationship (sweetheart scams) or fake charity donations.

It is recognized that, compared to other forms of family violence, elder abuse is under-researched (Yon et al. 2018). Much of the theoretical research on the topic is based at the level between two individuals; the older person and the perpetrator. Such constructions of dyadic abuse do not include institutional abuse or negative

consequences due to structural issues in society, for example, genderized discrimination, stereotypical ageist perspectives or ageist policy. Consequently, much work needs to be undertaken to examine how elder abuse manifests at the level of community and populations. Moreover, the bulk of scholarship is based on victims (Jackson 2016), and this has been considered as a barrier to developing a range of response systems (Wolfe 2003).

Challenges have presented in defining elder abuse and, as indicated, current perspectives on the topic increasingly link elder abuse to human rights. This has led to a concerted effort of replicating the success of the Convention on the Rights of the Child (UN 1992) and the Convention on the Rights of Persons with Disability (UN 2006) with debates in the United Nations on progressing a new bespoke convention championed by the Open-Ended Working Group on Ageing for the Purpose of Strengthening the Protection of the Human Rights of Older Persons.

While elder abuse is generally considered the domain of adult protective services (mainly under the remit of health and social care services), there is an increasing realization that responses need to be immersed in cohesive inter-sectorial, inter-agency collaboration within and between services such as health and social care, legal, forensic accountancy, financial services, policing, policymakers, housing departments, non-governmental organizations, independent advocates, and social protection departments. While there are fundamental overlaps with interpersonal violence such as issues of power and control, the taboo and closeted nature of abuse as well as the context of elder abuse grown old (where abuse is continued to old age rather than exclusive to old age) (Yon et al. 2014), there are also important differences. For example, ageist perceptions influence how older people are viewed and interacted with; the impact of paternalism is evident, particularly towards older people with cognitive or physical challenges (Phelan 2013, 2018). Within society, socially constructed dividing practices, such as age stratifications, can ascribe particular stereotypical views of age and underpin the 'othering' perspective; the perception that those of another age group are not quite the same as 'us', and this can lead to marginalization due to such taken for granted assumptions (Phelan 2018). Such marginalization has consequences, such as a higher tolerance to abuse activities, thus, lessening recognition as well as the impetus to intervene (Shah and Bradbury-Jones 2018; Phelan 2018).

Older people do not have the luxury of time in relation to recognition of the abuse, nor the same amount of time to rebuild their lives. Entrenched values of stoicism engendered over a lifetime, may mean a toleration of abuse and an internalization of the stereotype embodiment theory (where the older person adopts ageist stereotypes, believing the abuse is deserved) (Levy 2009) rather than help-seeking. Moreover, having a dependency may mean a bartering in the context of accepting abuse in order to prolong some physical and/or emotional contact, particularly with family. Older people can have a reduced social contact network, making it more difficult to access help, while simultaneously enabling a perpetrator to conceal the abuse. Thus, an older person who appears to withdraw from social contact can be more easily 'explained' (through ill health for example) than a child who is prevented from going to school or an adult who is absent from work or from community interactions.

Recognizing elder abuse has also been complicated by a conflation of the indicators of abuse with physical and cognitive decline (Bonnie and Wallace 2003). There are a number of screening and assessment indexes which have focused on increasing healthcare practitioners' ability to detect elder abuse and to initiate a referral. Some of the tools focus on an assessment of the older person (e.g. Fulmer et al. 1984; Yaffe et al. 2008; Sengstock and Hwalek 1987), or the caregiver (Reis and Nahmiash 1995; Wang et al. 2006) and there has been work undertaken on more specific screening tools related to individual typologies of abuse (Wang et al. 2007; Conrad et al. 2010). Some preliminary scrutiny has been undertaken into the efficacy of interventions (O'Donnell et al. 2015, see chapter by Phelan and O'Donnell), however this area requires additional examination to ensure adequate, appropriate and acceptable responses are available.

1.2 The Content of This Book

Within this book, the authors offer important insights into the topic of elder abuse. Some chapters present the current state of knowledge in relation to an aspect of elder abuse while other chapters provide country case studies on areas such as legislation and policy or advocacy and general awareness raising. This chapter, Chap. 1, provides a broad background on the topic of elder abuse upon which to base reading further chapters.

Chapter 2 by Phelan and Ayalon presents a debate on the impact of ageism on the perpetration of abuse. Ageism is the stereotyping of older people which engenders homogenous traits and can socially construct older people as different from other age groups, thus, enabling different treatment, which can be paternalistic or of a lesser standard. The chapter presents current understandings of both elder abuse and ageism and also contextualizes how these two phenomena intersect within the micro, meso and maco systems levels to create the potential for abuse and neglect.

Chapters 3 and 4 examine the issue of elder abuse in relation to legislation. In Chap. 2, Phelan and Rickard Clarke present the orientation of safeguarding legislation towards person centred principles which are underpinned by a human rights based approach and the centering of decision-making around the older person's will, preference, values and beliefs. Selected legal commentaries are presented to illustrate how court decisions have orientated towards the views and perspectives of the older person. In Chap. 4, Lowenstein and Doran use Israel as a case study to chart elder abuse and neglect's recognition and formal response systems (legislation and policy). The chapter also provides a depth consideration of the trajectory within four legislative generations which have increasingly championed the empowerment of the older person as well as early detection and intervention in elder abuse and neglect cases.

Chapter 5 (Teaster et al.) also examines how legislation and policy have expanded to ensure a greater safeguarding impact on older people. The chapter specifically examines the context of safeguarding in the United States and charts elder abuse as a social justice issue. The authors trace the origins of public interest in safeguarding to the

protective service units' demonstration projects of the 1950s and presents the increasing scope of legislation, policy and public funding in the prevention of and responses to elder abuse. In particular, the Elder Justice Act from 2010 and the Elder Abuse Prevention and Prosecution Act (2017) are presented as landmark advancements on safeguarding in addition to further legislative protections. The chapter also offers a review of international human rights based activities and age related declarations that illuminate important directions in ensuring equitable and safe lives for older people.

Chapters 6 and 7 explore two categories of elder abuse which require some additional research focus and practice development. In Chap. 6, Malmedal discusses the sexual abuse of older people. It is noted that within elder abuse, this form of abuse is the least acknowledged as older people are subjected to ageist stereotypes of being asexual. Sexual abuse of older people is defined as well as examining prevalence, risk factors, required responses and methods to enhance how society can address this form of abuse.

In Chap. 7, Day traces the recognition, manifestations, risk factors and definitions of self-neglect. Self-neglect is a complex issue which can be contextualized in a continuum of severity (intentional or unintentional) encompassing cumulative self-care deficits and behaviors, which may include environmental squalor and hoarding. Day presents ways of assessing the older person who is self-neglecting as well as appraising how care can be managed, balancing ethical issues and safeguarding concerns.

One of the most insidious methods of elder abuse is that of financial abuse as it can be perpetrated without the knowledge of and remote to the older person. Chapters 8 and 9 focus on this subcategory of elder abuse. In Chap. 8, Phelan presents understandings and contexts related to the topic of financial abuse. Financial abuse is very complex and impacted by issues of family inheritance, relationships and the possible need to rely on others to assist with financial matters. The chapter argues that having preventative protections decreases the risk of financial abuse (for example, power of attorney in place, money management programs) and having comprehensive, collaborative interagency responses can limit the perpetration and impact of financial abuse on older people. Most importantly, a cultural shift is needed related to the assumption of control of assets and paternalism in financial management as well as the dispelling the myth that family have an automatic right to the assets of the older person. Older people also need to be empowered to act against scams and fraud through opportunistic contacts (door-stepping, telephone, post, internet, phishing, vishing, smiching) which may prey on older people's experience of loneliness, irrational belief in the deception or simple naivety. Chapter 9 (O'Donnell) offers a way to combat financial abuse and describes an empowerment, co-design, educational and information campaign to support older people to protect themselves. This work, undertaken in Ireland, culminated in *Keep Control*, a multi-media educational and information campaign developed by older people for older people. The three pillars of the campaign are a website, a DVD and a resource or information pack. Through these pillars, information and resources are provided within five critical areas for financial self-protection: making a Will, implementing enduring powers of attorney, opening joint accounts and authorizing signatures, making decisions at critical life

events and protecting oneself on the doorstep. *Keep Control* adopts a strengths-based perspective which celebrates, protects and fosters the agency of older people. This understanding of empowerment describes a process by which people gain control over valued resources in order to make or influence decisions which affect their quality of life and well-being.

One of the high risk factors in elder abuse perpetration is that of cognitive impairment. Cooper and Livingston (Chap. 10) offer critical insights into this context of abuse pointing to the different dynamics within caregiving and the increased risk of self-neglect in older people living with dementia. For caregivers, the impact of caregiving for an older person with dementia, particularly where behavior and psychological symptoms of dementia are present and where there is increasing hours of caregiving, can lead to a context of abuse perpetration through dysfunctional caregiving. The authors caution against paternalism, particularly where the older person with dementia has decision-making capacity and decides to continue the association with the alleged abuser. Here, the focus is on mitigating risk. Research undertaken with caregivers (both formal and informal) of people living with dementia demonstrates a much high prevalence of abuse. Ways of combatting the abuse of older people living with dementia are discussed with a separate consideration of abuse of people living with dementia in formal settings, such as nursing homes and abuse by the family caregiver.

Chapters 11 and 12 discuss issues related to elder abuse in Lesbian, Gay, Bisexual and Transgender (LGBT) communities and issues related to elder abuse and gender. In Chap. 11, Gutman and colleagues reflect on the unique and often overlooked considerations in the domain of elder abuse related to LGBT where research and practice have predominantly focused on mainstream, hetro-sexual populations. The chapter highlights the variations of experience inherent in cultural differences and social perspectives and emphasizes the imperative of engaging with LGBT people to develop understandings and appropriate responses. Central to understanding is an intersectional approach which appreciates the unique interface of age, gender and sexuality of older LGBT people.

Penhale, in Chap. 12, provides a contextual backdrop to elder abuse and then examines the pivotal issues impacting on gender experiences of abuse. The chapter considers the issue of vulnerability and recognizes that it is predominately linked to both situational and circumstantial factors and is conceptualized as a risk factor in elder abuse and, similar to points made by Gutman and colleagues, points to the intersectionality of age, disability and gender. In addressing a gender-based response to elder abuse, the important issue of power relations is crucial to address. Further scholarship in the domain of theoretical advancement needs to acknowledge the diverse experiences and contextual factors which are impacted by gender. In doing so, the voices of older women and men need to be incorporated into elder abuse research to identify the differences in their abuse experiences. In this way, bespoke interventions and model projects which utilize empowerment and rights based approaches can be developed and evaluated for impact.

Chapter 13 examines a relatively new area of elder abuse scholarship, that of resident to resident aggression, occurring in nursing homes. Resident to resident aggression is constituted by categories which include physical, sexual, psychologi-

cal, financial abuse, humiliating behavior and social exclusion; this type of abuse has a general prevalence of approximately 20%. Resident to resident aggression can have a significant impact on the health and welfare of older residents. Goergen and colleagues point to dementia as one influencing factor in abuse perpetration, but for this population, resident to resident aggression can be aggravated by pain and depression. The chapter presents a recent mixed method study on resident to resident aggression in Germany. Findings demonstrate that this form of abuse is not unusual in nursing homes and that it is generally observed in older residents' common living areas. Risk factors include individual factors, interpersonal dynamics as well as the physical and social characteristics of the nursing home. The chapter concludes with recommendations on how to address resident to resident aggression, such as training and education for staff and attention to the spatial environment.

In Chap. 14, Phelan and O'Donnell present findings based on a study undertaken in the National Centre for the Protection of Older People, University College Dublin, Ireland (O'Donnell et al. 2015). The study applied a socio-ecological approach to exam interventions for elder abuse. Following an integrated review of the literature, 98 interventions were examined and identified within micro, meso, exo and macro systems. The papers were also categorized into either descriptive or experimental studies/papers. Findings demonstrated that there is a relative paucity in the evaluation of elder abuse interventions and that additional work is required, particularly, related to larger population based studies. In addition, comparison of studies is limited by issues of methodological approaches and structural conditions within each jurisdiction.

Chapter 15, authored by Yon and colleagues, contextualizes elder abuse as a serious public health problem which has dire consequences for the victims, their families and society. In Europe, it is estimated that 15.4% of older adults in the community and up to 33% of older adults in institutional settings experienced some form of abuse in the past year. The chapter summarizes the risk factors as well as prevention efforts in responding to elder abuse. Moreover, the chapter examines three broad questions: (a) how can the awareness among health policy on the extent of the problem of elder abuse be raised; (b) what prevention programs have countries implemented at national levels; and (c) to which extent have countries been developing national action plans to coordinate action against elder abuse? The chapter concludes with reflections on a way forward with a series of integrated actions to address elder abuse.

In Chaps. 16 and 17, the authors trace the impact of non-government organizations on safeguarding older adults using the case examples of Serbia and Ireland. In Chap. 16, Todorovic and Vracevic present the increasing focus on the abuse of older adults in Serbia through research, awareness raising and advocacy by the Red Cross organization. Three Serbian seminal research studies have identified the issues in family relationships, response organizations' case management and legal gaps which disempower older people and create challenges in safeguarding. The work undertaken has had a particular focus on the promotion of a human rights agenda with a concurrent involvement of the Red Cross at an international level. In Chap. 17, Taylor examines the role of independent advocacy in safeguarding vulnerable adults again highlighting the need to explicitly benchmark the treatment of older

people with human rights. Using Ireland as a case example, common issues which can limit rights and limit choices for older people are discussed. These include funding inequities between nursing home care and home care, misunderstandings on the meaning of 'next of kin' as well as the phasing out of the wardship system of legal decision making capacity management, and issues related to medical models of care. Taylor argues for an increased professional and public awareness of abuse as well as an integrated safeguarding system (with standards and training), which places a greater emphasis on strategy and tactics, rather than resources as well as accommodating various levels of advocacy to enable person centredness.

In reviewing all 17 chapters in this book, it is hoped that a broad and inclusive consideration of the topic of elder abuse is provided. However, this book represents aspects of scholarship pertaining to elder abuse at this point in time. As the knowledge base expands and new insights are constructed, better conceptualizations and insights will be produced. Nonetheless, from contemporary understandings, what has emerged is the need to have sustainable responses that are effective and efficient yet flexible and person centred to adapt to the particularities of the abuse case. An essential component of such interventions is the involvement of the older person as much as possible so that interventions and responses integrate the voice of the older person and privileges their will, preference, values and beliefs. This can present an uncomfortable position for those involved in safeguarding, whose judgment of risk precludes the facilitation of acceptable risk and the identification of strategies to reduce or mitigate such risk. What is needed to enhance professional decision-making is a rights based approach incorporating the authentic involvement of the older person as much as possible. Within intervention systems, having timely responses, specialist multi-disciplinary teams, forensic centers, enhancing legal processes and elder death review teams are fundamental. As with all interventions, their evaluation in terms of acceptability and outcomes is essential and should comprise the involvement of all stakeholders. Only then can we provide comprehensive and appropriate responses to the societal challenge of elder abuse.

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Chapter 2
The Intersection of Ageism and Elder Abuse

Amanda Phelan and Liat Ayalon

2.1 Introduction

Within the twenty first century, there is a social transformation with the global success of longevity as populations' age. The demographic transition points to both an increasing life expectancy and a greater proportion of older people. For example, the average global life expectancy has more than doubled since 1900 (Roser 2018) with life expectancy at birth being 72 years in 2016 (WHO 2018) as compared to just 53 years in 1960 (World Bank 2018). Projected figures point to a doubling of people over 60 years from 962 million in 2017 to 2.1 billion in 2050 and 3.1 billion in 2100 (United Nations 2017). While this represents a major success in human longevity, the extension in quantity of years demands a concurrent optimization of quality of life (Phelan 2018), particularly related to the ability to live a life free from abuse.

Abuse occurs when there is a failure to respect the individual humanity of the older person. Age is an important dimension of social status and is intrinsically linked to culture and socio-historical experiences (Roscigno et al. 2007). Nelson (2005) recognizes the implicit human propensity of categorization within areas such as gender, race and age which can result in stereotyping and prejudicial treatment. Ageism has been described as the systematic discriminatory treatment of people because of their age and elder abuse represents the individual experience of maltreatment. Elder abuse refers to how older people can be treated in a negative way which can be manifested in physical abuse, psychological abuse,

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material/financial abuse, sexual abuse and neglect. In addition, Harbison (2016: 284) argues that ageism is inherent in many states' political discourses of older people as 'an unaffordable social and economic burden' and this is intricately linked to the conditions enabling abuse. In this chapter, we consider how elder abuse and ageism, as a categorization of social perception (Nelson 2005), intersect. We examine how ageism can be a permessor, (a factor which enables maltreatment to occur) and then discuss how ageism intersects with elder abuse at the macro-level, meso-level and micro-level.

2.2 Elder Abuse

Elder abuse was the last form of family violence to be formally recognized. Similar to child protection (Kempe et al. 1962), its recognition emerged within the field of medicine (Baker 1975; Burston 1975), while domestic violence emerged in the late 1960s from a feminist discourse, recognizing the power imbalance within gender relations. Elder abuse is defined by the WHO (2008: 6) as:

> …a single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust that causes harm or distress to an older person.

While this definition has some impetus, there are inherent challenges. The definition constructs abuse within a relationship as well as inferring that the maltreatment must have an impact (harm or distress) to constitute abuse. As such, abuse is then defined by *who* the perpetrator is and necessitates some consequential negative experience, rather than abuse as an independent act in itself. More recently, definitions have sought to be more inclusive and a particular focus on benchmarking abuse to human and civil rights has been apparent (WGEA 2002; WHO 2002; HIQA 2016; Purser et al. 2017). Definitions are influenced by issues such as interpersonal relationships, a lack of discrimination between normal and abusive interpersonal conflict and can also be limited by scant attention towards ageism, culture and social circumstances (Mowlam et al. 2007; Phelan 2013).

Another factor in understanding elder abuse is that definitions can differ according to professional discourses; for example, legal, case management and research definitions can vary. Legal definitions draw on abuse due to a crime being committed, case management definitions relate to making clinical decisions based on eligibility to services and the provision of information evaluating the context while research definitions guide the parameters of a study (Phelan 2010).

Elder abuse is perpetrated in many ways, through physical abuse, psychological abuse, material/financial abuse, sexual abuse and neglect. There is some debate on the inclusion of self-neglect as a category of elder abuse. For example, the Adult Protective Services in the United States recognizes self-neglect as a form of elder abuse, yet, up until 2014, Ireland's elder abuse policy (WGEA 2002) specifically excluded self-neglect, although due to the volume of self-neglect referrals, the health service accepted serious cases of self-neglect from the late 2000s.

Moreover, there is a difference in understandings of categories of elder abuse. Studies examining how older people themselves construct elder abuse differ from the traditional categories cited above and point to perspectives imbued with cultural representation as well as the individual's own personal ageing experience and values (Mowlam et al. 2007; Phelan 2010). For example, older people have pointed to categories based on abandonment, social isolation and social exclusion, human, medical and legal rights, decision-making abuses or a lack of respect (WHO and INPEA 2002). In a Swedish study, Erlingsson et al. (2005) facilitated focus groups with older people to generate understandings of elder abuse. Findings pointed to a more sociological level perception of elder abuse with participants observing a changing society with poor government priorities, understaffing in services important to support older people (law and health), negative attitudes to older people, a lack of staff with expertise in aged care, unstable family units and specific perpetrator factors. Taylor et al. (2014) argue that prioritizing older people's subjective experiences, in terms of defining what elder abuse is, enables a more comprehensive understanding and contributes to the prevention of ageism.

Theories of elder abuse frequently focus on the dyadic relationship between the older person and the perpetrator(s) and can reflect ageist perspectives of dependency and vulnerability. These include dyadic frameworks namely the caregiver stress/situational theory, the social exchange theory, the domestic violence theory, the psychopathology of the abuser theory, the symbolic interaction theory and the social learning/intergenerational abuse theory. These are briefly outlined below. For additional information see Phelan (2013):

- *Caregiver stress/situational theory:* This theory suggests abuse happens as the challenges of caregiving increase. The incremental stress experienced by the caregiver provides the context for abuse occurring.
- *Social exchange theory:* Relationships are built on 'give and take' where there are mutual benefits for individuals. As an older person ages, dependency may increase and the 'demands' on the caregiver may grow, while the benefits of the relationship are considered diminished. This imbalance may create a conflict environment as well as resentment and anger due to the reduced rewards within the relationship. Attempts to redress this imbalance may be constituted by threats of abuse or actual abuse. This theory assumes that relationships are based on maximizing benefits and minimizing costs In addition, neglect may occur due to ignoring the increased care demands and consequently, reciprocity becomes eroded (Phelan 2013).
- *Domestic violence theory:* This theory may in some cases, simply reflect domestic violence grown old. Elder abuse statistics frequently show that women are more likely to be abused than men (Naughton et al. 2010; WHO 2018). Consequently, this theory draws on feminist arguments of power imbalances related to gender inequality, emphasizing the social and structural conditions that may precipitate abuse (Yllo 2005).
- *Psychopathology of the abuser theory:* This theory considers that there are some innate characteristics the abuser holds which predispose to abuse. For example, the

abuser may have a mental health challenge, intellectual disability or a personality disorder, which prevents him/her from engaging in the care expectations of the relationship with the older person and these circumstances can predispose to an abuse situation (Norris et al. 2013). Equally, the abuser may have a substance abuse or alcohol problem which leads to distorted thinking and a need to fulfill their addiction. For example, the need to fulfill the addiction may lead to financially abusing the older person, psychological abuse or physical violence.

- *Symbolic interaction theory:* Drawing on the work of George Herbert Mead, symbolic interactionism is based on how we interact and mediate our interactions with others. Culture has a major influence on symbolic interactionism, however, the individual relationship may be underpinned by the abuser mediating behaviours by how successful they may be. This is particularly seen in the context of families ageing and roles changing, creating tension within families.
- *Social learning/intergenerational abuse theory*: This theory is based on the premise that behavior is learned. Thus, abuse is a normal and acceptable way of addressing conflict which may be transmitted from generation to generation and may occur within relationships at any age.

Other more macro-perspective theories of elder abuse such as the political economy theory and the ecological theory and can also reflect ageism. For example, the politico-economic theory addresses how older people are marginalized in society, which reflects an ageist perspective (Wolf 2003). Policy may dictate that older people are required to leave the workforce at a particular age and this can be compounded by losing roles and reducing independence, which may lead to elder abuse (Abolfathi-Momtaz et al. 2013). Retirement, as a social practice, has been linked to ageism (McDonald 2013).

The ecological theory, which is elaborated in this chapter, draws on the work on Bronfenbrenner (1979) and centres on systems' levels from the micro-system to the macro-system (also see Phelan and O'Donnell's chapter in this book). All of us are embedded in complex systems which range from our direct environment (i.e. family) to national and international influences on our lives (legislation, human rights).

The impact of ageism as a contributory factor in elder abuse perpetration has been conceptualized under an ecological lens in recent studies (Norris et al. 2013; O'Donnell et al. 2015; Dow et al. 2018). Within all system levels, ageist practices can lead to marginalization, constructing older people as 'others' (Dominelli 2003; Walsh et al. 2010) and not being quite the same as younger generations, enabling paternalistic treatment.

Norris et al. (2013: 52) suggests that the conceptualization of elder abuse requires a particular critical ecological examination, which demands an appreciation of multiple influencing factors (including ageism) which give rise to the conditions of possibility of elder abuse:

> Further exploration [of elder abuse] is needed on several fronts—the intersection between ageism with patriarchy, capitalism, and familialism and the way in which ageism transcends gender; the development of frameworks that position older adult abuse as a collective social program…

Thus, it is this crucial inter-sectionality between ageism and abuse which contributes to the conditions of possibility of abuse.

2.3 Ageism at the Macro Level

Ageism is defined by the World Health Organization as the way we think, feel and act towards people because of their age (Officer and de la Fuente-Núñez 2018). Ageism can be both positive and negative and can be directed towards people of all age groups (Officer and de la Fuente-Núñez 2018). However, the majority of research to date has focused on ageism as the negative construction of old age. Ageism can be both explicit and implicit and can be directed towards others but also towards oneself (Ayalon and Tesch-Römer 2017). Ageism can occur at the individual level, interpersonal level and at the societal level (Ayalon and Tesch-Römer 2018).

Ageism is manifested in laws and legislations as well as in what these laws and legislations target or refrain from targeting. In 1948, the United Nations (UN) General Assembly adopted a Universal Declaration of Human Rights, emphasizing the fact that all individuals have the same rights. Yet, seven decades later, age is still not an explicit part of a UN declaration[1]. Direct associations between human rights and elder abuse have been noted (Phelan 2008; Biggs and Haapala 2013). Human rights are positioned as benchmarking standards against which human experience can be viewed. Equally, a human rights agenda points to the legal obligations of states to address and remediate discrimination (Sepúlveda and Nyst 2012). However, Biggs and Haapala (2013) caution against an unproblematic and uncritical link between ageism, human rights and abuse, suggesting a critical assessment of the quality of the boundary between society, self and other needs. Consequently, issues such as adult to adult relationships, autonomy and social expectations need to be considered in the inherent wider social context (Biggs and Haapala 2013).

Much of the discussion of old age and ageing at the European level, for instance, has been colored by ageist attitudes, describing older adults as a challenge to society (Georgantzi 2018). Similar perspectives have been noted in other regions, for example, Canada (Harbison 2016). Age remains the only basis on which discrimination at the European level is still considered legitimate (Georgantzi 2018). Moreover, the use of terms such as the dependency ratio as a measure of older people's limited value to society also results in equating old age with being a burden to or redundant in society (Georgantzi 2018). It is expected that this view of old age and the legitimization of discrimination based on age reduces the awareness of elder abuse and neglect and possibly makes elder abuse more permissive for policy makers and legislators. This perspective is supported by Angus and Reeves (2006) who suggest that ageism positions older people as inferior and elder abuse can be tacitly tolerated (McDonald 2018). Thus, ageist perspectives within the macro-context of society are operationalized through individual experience. For example, in the case

[1] http://www.helpage.org/what-we-do/rights/towards-a-convention-on-the-rights-of-older-people/

of financial abuse, many studies point to the cultural sense of entitlement of younger generations to assume ownership, unproblematically, of the assets of older people; the perspective being the older person doesn't need the money, which is to be inherited by younger generation in any case. Equally, if abuse of older people as victims of crime enters the legal system, there is also evidence of ageism in terms of less favorable access to procedural justice, in this context, the legal system failing to accommodate for older people's distinct needs, which subsequently negatively impact on successful crime outcomes (Brown and Faith 2018).

Within many countries, if an older person's independence becomes challenged due to cognitive or physical decline, admission to long-term nursing home care becomes necessary. However, from a cultural perspective, admission to a nursing home can itself be seen as abusive. In China, for example, the Confucian principle of filial piety translates to the expectation that children will look after their older parents (Kim et al. 2015). However, there appears to be a resistance to such cultural values as it is noted that there is growing resentment in taking on the responsibilities of caregiving, as traditional values of respect and honoring elders decreases (Compernolle 2015).

2.4 Ageism at the Meso Level

Oftentimes, ageism occurs in social interactions between older adults and the general public (Kite et al. 2005), among older adults (Ayalon 2015) and between older adults and various professionals, including health and long term care providers (Kane and Kane 2005; Wyman et al. 2018). Ageism can potentially incite or intensify the occurrence of elder abuse and neglect in any of these instances. When interacting with others, a view of older adults as a burden to society, as slow to respond and as irrelevant might result in their exclusion from the public sphere (Clarke and Griffin 2008; Minichiello et al. 2000). Under such circumstances, ageism is more likely to be unnoticed or even accepted.

Many studies have pointed to ageism in healthcare manifested through interactions, policy and organizational cultures (São José et al. 2017; Ben-Harush et al. 2017) and ageism has been linked to reduced care quality (Wyman et al. 2018; Bodner et al. 2018). Within healthcare professionals, it has been demonstrated that there is a preference to work with younger generations (Kane 2004; Lee et al. 2018).

Professionals may hold more accepting views towards abuse of older people. For instance, an experimental study, which relied on a case vignette, has found that social workers were more likely to identify intimate partner violence when the victim was a younger woman than when the victim was an older woman. In addition, they were more willing to support and treat the younger person (Yechezkel and Ayalon 2013). A study by Kane et al. (2010) demonstrated the impact of age on scenarios of domestic violence in couples aged between 30 and 75 years. Findings demonstrated a lesser appreciation of the severity of abuse in

the older couple. The authors point to challenging stereotypical assumptions that older couples were generally in a harmonious relationship and happy, thus raising awareness that intimate partner violence is ageless. Other forms of ageism by professionals might be instigated by the thought that older adults are asexual (Gewirtz-Meydan et al. 2018) and thus, are not subject to sexual abuse, for instance. Moreover, thinking that older adults are incapable of managing their own affairs might result in putting great power in the hands of others, who could potentially be abusive towards the older adult. This might also result in reducing older adults' autonomy (Tampi et al. 2018).

Ageism has been noted in studies based on residential care (Dobbs et al. 2008) and both Harris (2005) and Jönson (2016) make an overt link between ageism and abuse in nursing homes suggesting that ageist attitudes are a factor in abuse perpetration.

Prevalence studies of elder abuse demonstrate that abuse does occur in nursing homes. While many of these studies focus on examining the categories of abuse perpetrated in dyadic interactions, there is little research focusing on ageism and institutional abuse, although care scandal reports and regulatory body reports demonstrate activities that would be considered abusive (Francis 2013; HIQA 2018). Institutional abuse may be defined as:

> …the mistreatment of people brought about by poor or inadequate care or support, or systematic poor practice that affects the whole care setting. It occurs when the individual's wishes and needs are sacrificed for the smooth running of a group, service or organization. (Harrow Council n.d.)

Begley and Matthews (2010) link institutional abuse to ageist assumptions, stating that human rights may be eroded through such stereotypical negative views of older people. Some studies have demonstrated indicators of ageism, such as infantilization of older people, as being associated with abuse (Pillemer and Moore 1989; Bužgová and Ivanová 2009), with almost 11% of staff in an Irish study indicating that older people were like children and needed to be disciplined from time to time (Drennan et al. 2012). In a qualitative study on ageism and elder neglect in long term care facilities, Band-Winterstein (2015: 5) describes the link between ageism and elder abuse as the 'twilight zone'. Two themes were identified which illuminate ageism in care delivery. Firstly, the tacit normalization of neglect as older people are rendered transparent in everyday routines leading to the objectification of the older person within task orientation and economics rather than person centred care delivery. Secondly, the institutional approach minimizes the value of older people and there is a growing importance in bureaucratic activities as opposed to evaluating person centred outcomes. Both factors can result in ageist stereotypes, for example, being non-productive, dependent or asexual (Band-Winterstein 2015). Yet, a third theme pointed to staff's conscious knowledge of such poor systems of care and participants suggested ways to combat 'neglect in an ageist reality' (Band-Winterstein 2015: 9). These included increased multi-disciplinary input, reflective practice which priorities person centeredness as well as engaging in overt conversations on ageist practices.

2.5 Ageism at the Micro Level

Research has consistently shown that older adults internalize ageist messages throughout their lives (Levy 2001, 2009). This results in some older people thinking that, because they are aged, they are slow, useless, over the hill or a burden to society (Minichiello et al. 2000). Internalizing these negative messages might result in older adults being more reluctant to report events of abuse, as they already feel powerless and unnoticed in society. Moreover, older adults might be more likely to accept abusive experiences simply because of their negative self-evaluation. Thus, abuse may be tolerated or even unrecognized because of learned and accepted dependency positioning of older people in society. Within care environments, there can be a tendency to assume a paternalistic approach in the context of decision-making. This renders the older person 'voiceless' in his/her care and denies self-determination and autonomy, constituting an ageist agenda (Ward 2000; Doyle 2014). This is a particular issue in relation to decision making capacity, where families and/or healthcare staff can assume paternalistic positions or place undue influence on the older person based on age. Consequently, it is important that healthcare and social care professionals understand how to support individual human rights within care delivery and within society itself, so that rights are authentically experienced and enjoyed by all human beings regardless of age, decision-making capacity or paternalism from professionals or family.

2.6 Conclusion

Prevalence studies globally demonstrate that elder abuse is a challenge in many societies. In this chapter, we have considered the intersection of elder abuse and ageism drawing on an ecological, systems based approach. Ageism presents as a systematic stereotypical approach to older people manifested in behaviors, practices, attitudes and discourses (interpersonal and policy) within everyday life. In 2005, Nelson observed a link between ageism and elder abuse, arguing that ageist attitudes position older people as second-class citizens and enabled a higher degree of tolerance of neglect and exploitation. More recently, ageism as a contributory factor to elder abuse was identified (Norris et al. 2013; Dow et al. 2018), with earlier commentators suggesting that ageism impacts the understanding of elder abuse (Gelles 1997) as well as impacting formal reporting of such maltreatment (Podnieks 2006). While some work has been undertaken into the oppression of older people using the lens of ageism and elder abuse (McDonald and Sharma 2011; Brownell and Kelly 2013; Harbison 2016), a recent review of contributory factors points to the need for additional supporting evidence (Pillemer et al. 2016). Thus, more work is essential to understand the inherent power and culture dynamics as they are manifested within ecological systems. Imbalances in power can be due to multiple forms of oppression, including ageism, sexism, racism, poverty, disability, sexual

orientation which, either individually or combined, lead to heightened risk for abuse perpetration (Walsh et al. 2010). Consequently, for effective preventative and intervention responses to elder abuse, the conditions of possibility, which includes ageism, need to be addressed within multiple environmental systems.

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Chapter 3
Person Centred Approaches in Capacity Legislation

Amanda Phelan and Patricia Rickard-Clarke

3.1 Introduction

A major issue within safeguarding is upholding an individual's rights particularly related to free choice and making decisions autonomously. In this chapter, the concept of person centredness is presented and its relationship and impact on capacity legislation. Person centredness has emerged in the discursive space of health but its core principles are intrinsically linked to the wider concepts of rights, autonomy and self-determination. Where there are decision-making challenges, many states have progressed legislative protection to preserve and facilitate an individual's will, preference, values and beliefs. This represents a more integrated and cross sectional approach to person centred principles and concurs with a rights based approach. Rights may be viewed as encompassing both human rights, as detailed in the United Nations Declaration on Human Rights (UN 1948) and the United Nations Convention on the Rights of Persons with Disabilities (UN 2006) and citizenship rights which prescribe the state-citizen relationship (Phelan 2012). Both human rights and citizen rights are generally reflected in legislation representing a state's explicit expectations in terms of responsibilities, entitlements and duties both towards citizens and expected of citizens. Accordingly, current understandings of decision-making capacity are examined together with recent legal commentaries in the Ireland and the United Kingdom reflecting a person centred approach.

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3.2 Person Centred Care

The origins of the term 'person centred' lies within the field of psycho-therapeutics (Brooker 2003). Rogers (1951), an American psychologist, applied a humanistic approach using the term client centred care, which was, over the years, replaced by the term person centred care. Rogers (1980) proposed that core conditions were necessary to enable human growth and flourishing and relationships needed to be underpinned by congruence (genuineness), empathy and unconditional positive regard. While such concepts are fundamental in person centred care, more contemporary understandings can be traced to Tom Kitwood (1997), who, drawing on the work of Burber (1937), emphasized the essential nature of recognizing personhood in each individual regardless of cognitive or physical ability. As such personhood is an inherent essence of humanness and is commonly viewed as 'the attributes possessed by human beings that make them a person' (Dewing 2008: 3).

The challenge of ascribing a particular status or applying attributes for personhood has been noted (Dewing 2008; McCormack and McCance 2010). Personhood has been linked with traits such as rationality and thinking. For example, Decartes, a seventeenth century philosopher, defined a person through his famous idiom 'I think therefore I am', linking the meaning of being a person to the rationale mind. This suggests the diminishing of personhood when capacity and competence are challenged and being unheard and unrecognized is akin to 'absolute death' (Bakhtin 1984). Such benchmarking, typical of empirical functionalism, can lead to a hierarchy and exclusion of individuals who do not meet the required 'criteria'. Moreover, some of these common 'defining' attributes are not unique to humans (self-determination, language, thought, memory), but may be observed in animals, blurring understandings of personhood (McCormack and McCance 2010). Terms such as 'loss of self', associated with the progression of dementia related diseases, also tacitly suggest a loss of personhood where personhood is solely related to cognitive function (Buchanan and Brock 1990; Liebing 2008). Thus, the danger of an empirical functionalist approach, typical of the use of defining attributes to personhood, is that there may be consequences such as being treated in a lesser and unequal way (Fu-Chang Tsai 2009). Rather, personhood is dynamic, in continual development and flux, taking account of temporality and corporeality (Dewing 2008). Consequently, taking an ontological personalism approach is more helpful, inferring that all human beings are persons, regardless of attributes (Nelson 2009).

Kitwood (1997: 8) further contends that personhood is only actualized through our interactions with others within the context of relationships, requiring 'recognition, respect and trust'. It may be constructed as a status afforded within authentic interpersonal relationships (Penrod et al. 2007; Nolan et al. 2004). These descriptions have been subject to some critique, as they imply personhood exists within relationships, rather than a unique way of 'being'. Consequently, McCormack (2004) argues that 'being' is central to personhood and has four dimensions which represent each individual's life world: being in relation, being in a social world, being in place and being with self.

The aim of person centred care is prioritizing the individual's authentic wishes, appreciating their uniqueness, respecting rights, building mutual trust and the engagement in therapeutic relationships (McCormack and McCance 2017). Person centred care is underpinned by the fundamental equality and self-determination of human beings and the recognition and facilitation of what matters to that person (Liebing 2008). As such, people are entitled to make autonomous, informed choices and should be enabled and supported to participate in their care/lives at the level they desire (Ganzini et al. 2004; WHO 2015). Within health and social care, this represents a move from traditional bio-medical models to psycho-social models which transcend the narrow focus on the medical condition and tasks to the appreciation of the totality of the person and the context of their life experience, their personal values, preferences and life world, countering paternalism. Person centredness is essentially focused on putting people at the heart of care delivery where they experience positive benefits (WHO 2015). However, this requires a move beyond mere rhetoric to the transformation of care cultures enabling human flourishing (Richards et al. 2015).

Globally, there is a growing focus on person centred approaches within the context of health care reform (Harding et al. 2015; McCormack and McCance 2017). Person centred care has also been framed beyond the individual dyadic relationship to include a wider context (McCormack and McCance 2017; Harding et al. 2015). Further work by Kitwood and others point to the social and relational environment within which people with dementia live and suggest that a malignant social psychology fundamentally erodes their experience of personhood (Kitwood 1997; Todres et al. 2009).

In particular, McCormack and McCance's (2010, 2017) framework promotes the essential need for person centred cultures which require particular prerequisites of the healthcare professional, the care environment, the processes involved in delivering care and the need to evaluate outcomes. Work within person centred care has extended to person centred co-ordinated care (Phelan et al. 2017) and personalization agendas in healthcare (Manthrope and Samsi 2016) typified by consumer directed care (Phelan et al. 2018). Within the regulation of health, a person centred approach has been increasingly evident. For example, within the Irish Health and Information Authority (established in 2007) standards, policy documents are replete the need for care environments to centralize the individual's will and preference though person centred approaches.

3.3 Decision-Making Capacity

As indicated in the discussion on personhood, maintaining a person's will and preference is paramount, regardless of cognition challenges or physical appearance. However, decision-making is based on capacity. Decision-making capacity may be described as the ability of an individual to exercise self-determination and communicate this to others (Spike 2017). All people have a right to make an uninfluenced

and informed decision and this is fundamental to quality of life. Even when decision-making capacity is in question, people still value being involved or having their preferences authentically and genuinely represented (Featherstonhaugh et al. 2016). Decision-making is afforded legal status when consent is formalised (Walter et al. 2018). Flynn and Arstein-Kerslake (2014) argue that legal personhood is linked to the possession of decision-making capacity, where cognition and autonomy are intrinsically prized. Similar arguments are posited by Post (2006) who suggests that the loss of an individual's cognition translates to a cultural diminishing of their personhood. This leads to a situation of a social positioning of vulnerability and a consequent perception of a need to overprotect which, more insidiously, tacitly sanctions paternalism. Within person centred care, the 'voice' of the person is prioritized, however, practically, this often depends on the judgment of the healthcare professional that the person has decision-making capacity (Ganzini et al. 2004). Both Ganzini et al. (2004) and Spike (2017) emphasize the lack of distinction in healthcare practice related to decision-making capacity and competence. Although conceptually interlinked, decision-making capacity is a clinical based assessment of the ability of a person to make a particular decision, while competency is a legal appraisal of the person's ability to make decisions in general (Ganzini et al. 2004). While decision-making capacity challenges require clinicians to examine if there is a representative decision maker legally appointed, courts deliberate on competency and can appoint a representative decision maker.

Historically, in many countries, legislation has assumed a paternalistic approach (see Lowenstein and Doran in this book). For example, the Lunacy Regulation Act (Irish Statute Book 1871) in Ireland enabled a system of wardship for those deemed to be incapacitated. Most often, the foundations for granting wardship were entrenched in a status approach to capacity, based on medical cognitive testing rather than actual ability to make individual, informed decisions. Indeed, Spike (2017) observes that challenges to decision-making capacity often invoke (erroneously) a psychiatric consultation and many of the assessments are based on tests developed for dementia rather than decision-making capacity and are comprised of the various mental status exams. Spike (2017) further argues that the misuse of this test can lead to false conclusions. Moreover, the stimulus to suspect decision-making capacity challenges could simply be the individual having a different opinion to the doctor/nurse. Conversely, there can also be a myth that agreeing with healthcare practitioners means there is no need for decision-making capacity assessment although informed consent may, in fact, be absent (Ganzini et al. 2004).

Assessing capacity presents a moral, legal and ethical challenge in health, legal and social care environments (Pennington et al. 2018) and is dominated by two fundamental ethical principles-autonomy and protection (Moye et al. 2013; Marson et al. 2009). In general, there are three approaches to decision-making capacity, namely, the status, outcome and the functional approaches. The status approach to decision-making capacity translates to an all or nothing approach. Thus, once deemed incapacitated under this legislation, decisions are (generally) made without recourse to the individual. Deemed not to have decision-making capacity, this is the

standard for all levels of decisions; in other words, cognitive impairment means there is a permanent lack of decision-making ability which may be automatically linked to certain medical or psychiatric diagnosis or involuntary admission to psychiatric hospitals (Ganzini et al. 2004). Thus, in the case of wardship, a substitute decision maker is appointed. Such guardianship arrangements are seen to be disempowering and contrary to Article 12 of the United Nations (UN) Convention the Rights of People with Disabilities (Flynn and Arstein-Kerslake 2014).

Another perspective, the outcome approach focuses on the perceived poor consequences of the decision; it is subjective. Thus, if deemed a risky decision, the individual may be considered not to have relevant decision-making capacity and consequently denied independent decision-making ability. Both the status and outcome approaches are contrary to person centredness and are underpinned by a paternalistic perspective.

The third approach to decision-making capacity is the functional approach. This is founded on the principle of always assuming decision-making capacity unless otherwise proven and is time, issue and decision specific. Functional approaches are based on the person having relevant information in an appropriate format, being able to retain and weight up the options (reasoning), making a voluntary decision and being able to communicate the preferred option. This facilitates an appreciation of fluctuating capacity and recognizes that decision-making capacity can depend on issues such as level of complexity, amount of information, understanding and the competency of the communicator to support the person and assist in optimizing and augmenting understanding and enabling compromise when a decision is impossible (Featherstonhaugh et al. 2016).

While there are a number of published capacity assessment tools, there is not any consensus on a standard approach although dedicated capacity training does increase inter-rater reliability (Pennington et al. 2018). Equally, Pennington et al. (2018) observe that some of these tools may contradict legislative imperatives in both the United Kingdom and Ireland, such as the explicit expression of choice or the need of choice to be rational. Capacity tools that have been used are, for the most part, tools which assist with a clinical diagnosis focusing on a disability (the medical model) rather than on the person's ability to make a decision. Thus, such tools need 'cultural proofing' to ensure they align with contextual use as well as ensuring the evaluator (i.e. health care professional) understands the principles of appropriate assessment using a functional approach.

Within progressive diseases such as dementia, the executive functioning of the brain, which controls higher order and abstract thinking can deteriorate first (Guarino et al. 2019). Accordingly, decisions around the management of finances can be a first indication of challenges in decision-making capacity. Specific financial capacity assessments can be useful to assess financial management ability and importantly, enable the person to take appropriate steps (Martin et al. 2008; Marson et al. 2009) and further support can be provided in the context of continued decision-making deterioration. What is required is what Flynn and Arstein-Kerslake (2014) identify as an accessible continuum of support which is scaffolded by enabling conditions (advocacy,

advanced care decisions and options to multi-modal communication options) to prioritize a person's will and preference. Moreover, the socio-cultural aspect of capacity needs to be appreciated, which includes life experience, genderized roles, religious and ethnic perspectives on decision-making (Pennington et al. 2018).

3.4 A Rights Based Approach

Historically, personhood has been linked to the exercise of rights. Freeman and Fraser (1994) observed how gender relationships limited personhood. Women's right to vote is only a relatively recent social and political achievement and the concept of coverture, derived from English law, meant that women who married were considered the chattel of their husbands thus hindering their rights and their experience of personhood (Finn 1996). Yet, the limitations to personhood extend beyond gender. Rights can often be curtailed within marginalized groups, justifying discrimination. Within the social control of dominant groups, there has been a hierarchy of rights based on issues such as age, citizenship, ethnicity, religion, caste, legal status, social class, socio-economic group, disability (physical and/or cognitive), thus positioning marginalized individuals as 'others'. Such social distinctions typified rationales for different and unequal treatment which could also be supported in law. For instance, prior to a legislative amendment in 1865, slaves in America were considered three fifths of a person (US Constitution Amendment 1865), while the instigation of the 1935 Nuremberg Laws in Germany sanctioned the discrimination (and depersonalisation) of the Jewish people laying the foundation for the Holocaust (Heideman 2017).

While the concept of rights can be traced to the Code of Hammurabi (cica 1780 BC) and the Cyrus Cylinder (580 BC), modern understandings stem from the middle of the twentieth century. There are two major lenses to consider rights-citizenship rights and human rights. Both have an advantage over the concept of personhood as a rights-based approach enables a political dimension to be explored and also is concerned with power dynamics (Bartlett and O'Connor 2007). Although both types of rights have similar and somewhat overlapping conceptual bases, there are fundamental differences. Dominelli (2014) observed that human rights place an obligation on nation-states to guarantee rights articulated by its 'duty to care' to its citizens, which connects human rights to citizenship and national sovereignty. As such, both human rights and citizen rights are important benchmarks to examine standards of equality, equity and social justice. Rights are important tools to highlight discrimination, particularly for marginalized groups such as those who have decision-making capacity challenges. As human rights are frequently aligned with decision-making capacity, citizen rights are briefly considered before a more in-depth review of human rights.

3.4.1 Citizen Rights

Our modern concept of citizenship is premised on having a particular social identity and belonging within national boundaries. Citizenship is a defining concept in state-individual relations and has been subject to change being immersed in history, social issues and political ethos. Theodore Marshall (1950) identified citizenship as developmental and evolutionary, based on equality and comprised of three domains, namely, social rights (welfare, food, shelter, healthcare), political rights (including voting) and civil rights (freedom of speech, right to own property). While these domains remain useful in delineating responsibilities of the state towards citizens, more recent commentators note the need to expand understandings because of a changed and transformed political and social landscape due to issues such as supra-national integration and more fluid immigration patterns (Guarnizo 2012).

3.4.2 Human Rights

The UN came into being in 1945 and its main purpose is to promote respect for human rights through international co-operation. The Declaration on Human Rights was produced in 1948 to delineate fundamental freedoms belonging to all human beings. The focus of the Declaration was to ensure the atrocities of World War II were never repeated. The Declaration did not directly create legal obligations for states as it was not a treaty but it has had a profound influence on the development of international human rights law. The European Convention for the Protection of Human Rights and Fundamental Freedoms was adopted in 1950 and came into force in 1953. It was the first instrument to give effect to certain of the rights stated in the Universal Declaration of Human Rights and make them binding on States. Since its adoption in 1950, the Convention has been amended a number of times and supplemented with many rights in addition to those set forth in the original text (European Court of Human Rights and Council of Europe 2013). Human rights are considered interdependent and indivisible and may be supported through various international and regional treaties as well as legislation (IHREC 2015). The core features of the human rights treaties are the right to equality and non-discrimination, the right to life, right to liberty, right to respect for private and family life but in spite of such provision it has been necessary to develop treaties to ensure the respect the rights of specific groups such as Convention on the Rights of the Child (UN 1989) and Convention on the Rights of Persons with Disabilities (UN 2006).

The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted in December 2006 and entered into force on 3rd May 2008. It is the first comprehensive human rights treaty of the twenty-first century and is the first human rights convention to be open for signature by regional integration organizations (UN 2006). The European Union ratified the CRPD in 2010. While the CRPD did not introduce new rights it followed decades of work by the UN to change attitudes and

approaches to persons with disabilities. It takes to a new height the movement from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (UN 2006).

The purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (Article 1) and clearly sets out State Parties obligations for the purposes of the convention. Article 3 sets out the general principles which include respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity and accessibility. Article 4 sets out the general obligations for States to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized by the CRPD and to undertake to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.

In relation to States obligations, the CRPD is particularly directive with regard to their obligation to ensure the right to equal recognition before the law of all persons with disabilities. Article 12 provides that State Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law but also to recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Legal capacity was not defined in the CRPD but helpfully the UN Committee on the CRPD defined legal capacity as the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). The Committee confirmed that legal capacity is the key to accessing meaningful participation in society. Wilson (2017) stated that in any interpretation of the term 'legal capacity' it is crucial that there is a clear understanding that legal capacity is conceptually very different form the concept of mental capacity. The concept of mental capacity refers to the ability of individuals to make decisions for themselves – either on their own or with support, whereas by contrast, legal capacity is a legal status or standing. Traditionally laws have conflated these two concepts and denied persons who had difficulty making decisions of their fundamental legal status of 'legal capacity' which they hold as human beings. Article 12 also imposes obligations on States to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity thus ensuring full and effective participation by people with disabilities not only in their own lives but also in society.

Ireland signed the CRPD in 2007 but did not ratify it until March 2018. The reason for the delay was that the implications of ratification is that a State is obliged to ensure that its domestic legislation complies with the treaty provisions and is subject to reporting obligations to the UN Committee to monitor compliance with international human rights law. To enable ratification, Ireland enacted the *Assisted*

Decision-Making (Capacity) Act (Irish Statute Book 2015 Act) (discussed below) in 2015.

While Ireland is to the fore in its compliance with the CRPD, the 2015 Act currently does not make any provision for compliance with Article 14 of CRPD which relates to liberty and security of person. New legislation is anticipated which will add to Part 13 of the 2015 Act to provide a legislative framework for protection of liberty safeguards for persons with disabilities.

The protection of human rights continues and there is now a growing realization that yet a further international convention is required as existing human rights mechanisms fail to adequately protect and promote the rights of older people. The UN established the Open-ended Working Group on Ageing in 2010. Its purpose is to strengthen the protection of older people's rights by reviewing how existing instruments address older people's rights, identify gaps in protection, and explore the feasibility of new instruments (Help Age International n.d.).

3.5 The Legislative Turn to Person-Centredness

This section examines the case of the Irish Decision Making Capacity Act and also considers legal commentaries which have underpinned an increased legal appreciation of the concept of person centrerdness. This has been demonstrated by supporting an individual's self-determination, authentic voice and happiness.

3.5.1 The Assisted Decision Making Capacity Act: Placing the Person First

In December 2015, new Irish legislation was signed into law. This updated the archaic 1871 Lunacy Regulation Act based on a status approach to capacity. Within the mental capacity legislation in the United Kingdom (2005), the term 'best interests is used rather than will and preference. Flynn and Arstein-Kerslake (2014) point to the subjectivity in the term as 'best interests', like beauty, is in the eye of the beholder. Rather, Irish legislation applies the principles of supporting the person's will, preference, values and beliefs. The 2015 Act establishes a modern legal framework to support decision-making and sets out a number key principles (Guiding Principles) that apply before and during any intervention in respect of a person who may be the subject of the legislation. An intervention, defined as an action taken, orders made or directions given under the Act, in respect of a person, must be in a manner that minimizes the restriction of the person's rights and the restriction of the person's freedom of action and have due regard to the need to respect the right of the person to dignity, bodily integrity, privacy, autonomy and control over his or her financial affairs. The Guiding Principles also include the participation by the person in any intervention in so far as practicable and the giving

effect to the past and present will, preferences, beliefs and values of the person in so far as reasonably ascertainable (Section 8 2015 Act). From the Irish perspective, the 2015 Act provides that the capacity of all existing adult wards of court will, on the commencement of the new legislation, be subject to a review. The applications of many wards will have been based, as stated above, on the status approach to capacity whereas the 2015 Act provides that a person's capacity (to include wards subject to review) is to be construed functionally and provides that a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of available choices at that time (Section 3 2015 Act). All wards will be discharged from wardship and those that continue to need support will transition to the supported decision-making arrangements contained in the 2015 Act.

The Act also enables a spectrum of legal supports to enable the will, preference, values and beliefs. In the context of having decision making capacity, an individual can arrange to have an advanced healthcare directive or arrange an enduring power of attorney. This enables them to select a person who will act on their behalf (according to the Guiding Principles). For those who are experiencing decision-making capacity challenges, there are three options which allow for different levels of decision making capacity. Firstly, an individual can have a decision-making assistance agreement. The appointed person will access and help to explain relevant information and discuss issues with the person, but the decision remains with the individual. Secondly, a co-decision maker is chosen by the individual to assist in the same way as the decision making assistant, but makes the decision with the individual. For individuals who do not have decision making ability, a decision making representative may be appointed by the Circuit Court to act on behalf of the individual and according to the Guiding Principles, which are underpinned by directing decisions according the individual's will, preference, values and beliefs.

3.5.2 Legal Commentaries Underpinned by a Person Centred Approach

While the philosophy of person centredness has existed in health for a number of decades, recent legal discourses have sought to reiterate the central concepts of autonomy and self-determination. Case law in Ireland as far back to 1996 has considered capacity to make decisions as requiring a legal assessment. In *In re Ward of Court (withholding medical treatment) No. 2*[1996] 2 I.R. 79, the Court stated that an adult is presumed to have capacity and whether a person has capacity to execute an instrument requires an understanding of the nature, purpose and effect of an instrument executed by him or her. In *Fitzpatrick v. F.K.* [2008] IEHC 104, the court linked the question of capacity to the ability to understand information, understand the consequences of an action, of a choice made and to be in a position to weigh information an alternative choices and likely outcomes. In SCR [2015] IEHC Baker J. stated:

> I consider then that the question of cognitive capacity requires the court to make a legal assessment of such capacity and that the court ought not, in the case of the execution of an instrument creating an EPA, defer to a medical assessment even one made following a contemporaneous or near contemporaneous assessment.

Justice Baker concluded that the '*test is a legal test*' The legal test has now been given statutory effect in the Assisted Decision-Making (Capacity) Act 2015 which provides that:

> A person lacks the capacity to make a decision if he or she is unable –
>
> to understand the information relevant to the decision,
> to retain that information long enough to make a voluntary choice,
> to use or weigh that information as part of the process of making the decision, or
> to communicate his or her decision…by any means…(Section 3(2) ADMC Act 2015)

In particular, commentary by various judges in the United Kingdom point to the imperative of including the person's voice and perspective in care. In the case below, Re M., the person did not wish to remain in a nursing home, despite relevant authorities lobbying to have her legally detained there:

> In the end, if M remains confined in a home she is entitled to ask "What for?" The only answer that could be provided at the moment is "To keep you alive as long as possible." In my view that is not a sufficient answer. The right to life and the state's obligation to protect it is not absolute and the court must surely have regard to the person's own assessment of her quality of life. In M's case there is little to be said for a solution that attempts, without any guarantee of success, to preserve for her a daily life without meaning or happiness and which she, with some justification, regards as insupportable. (Jackson 2013)

The paternalistic approach to care is also represented in the excerpt below, where Judge Eldergill points to the function of authorities as serving the person rather than assuming authority over decision-making:

> Therefore, it is her welfare in the context of her wishes, feelings, beliefs and values that is important. This is the principle of beneficence which asserts an obligation to help others further their important and legitimate interests. In this important sense, the judge no less than the local authority is her servant, not her master. (Eldergill 2014)

Fundamentally, these commentaries have considered how care authorities place a major focus on risk, without appreciating that making an unwise choice is an entitlement for people who demonstrate functional capacity and objective capacity assessment is essential underpinned by supported decision-making:

> …risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective. (Baker 2012)

Enabling authentic decision-making involves a sensible approach, which also considers the person's happiness. Paternalism may work at the extreme of taking the outcome approach to capacity, where unwise decisions are deemed untenable.

> The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable? (Munby 2007)

Consequently, assessment of risk within decision-making requires a careful deliberation on the balancing of rights:

> Risk cannot be avoided of course. All decisions that involve deprivation of liberty or compulsion involve balancing competing risks, of which the risk that others may suffer physical harm is but one. For example, detention and compulsory care or treatment may risk loss of employment, family contact, self-esteem and dignity; unnecessary or unjustified deprivation of liberty; institutionalisation; and the unwanted side-effects of treatment. (Eldergill 2014)

In Ireland, it will be interesting to see the practical implementation of the 2015 Act when fully commenced and the giving effect to and interpretation by the court of the principles set out in the Act.

3.6 Conclusion

This chapter has examined the concept of person centredness and how its central principles of individualism, self-determination and intrinsic worth of every human being has been supported through human and citizen rights discourses and within contemporary legal discourses. An individual's will, preference, values and beliefs are fundamental to enabling personhood. Consequently, it is imperative that professionals and society recognize and defend the right of all people to make decisions and to act on their own behalf. Human rights are everyone's business and are important in every setting and for every person. To conclude, it is useful to consider the words of Eleanor Roosevelt (1958), who chaired the Human Rights Commission and was a pivotal force in the establishment of the Declaration of the Human Rights (UN 1948).

> Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world. … Unless these rights have meaning there, they have little meaning anywhere. Without concerned citizen action to uphold them close to home, we shall look in vain for progress in the larger world.

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Chapter 4
Elder Abuse in Israeli Society – Legislative Acts and Special Services

Ariela Lowenstein and Israel (Issi) Doron

4.1 Introduction

The demographic structure of developed societies is changing, and rates of older persons are constantly increasing. Thus, in Article 25 of the Charter of Fundamental Rights, the European Union already recognised and respected the rights of older people to lead a life of dignity and independence, and to participate in social and cultural life. Accordingly, the challenge today and for the future will be to tackle this demographic change in an affirmative way, eschewing any sense of old age being a burden on society or posing a threat to the individual.

Part of this challenge includes combating elder abuse and neglect – a relatively neglected issue that still tends sometimes to be trivialized and pushed into the background. Older people who are dependent on care and/or are isolated within their own homes, or in care facilities, are especially prone to it. Care in the home brings with it several strains, not least for the health, wellbeing and social contacts of those providing that care. Families sometimes must sacrifice a great deal to look after older relatives. Caring for older people who suffer from dementia presents a special strain.

The ability of families today to continue providing care for frail elders in view of changing family structures, increasing female participation in the workforce, changing work-life balance and longer working life (Daatland and Lowenstein 2005; Attias-Donfut and Wolff 2003) is becoming thus more difficult. All this may lead to incidences of abuse and neglect.

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Elder abuse is still one of the most hidden forms of mistreatment and a key to governmental responses to an ageing population. It is an important facet as a family violence problem, an inter-generational concern, as well as a public health, justice and human rights issue. Neglect, abuse and violence had been already identified at the 2002 Second World Assembly of Aging in Madrid (MIPAA 2002) as an important issue affecting the well-being of older people around the world, and since then have received a growing global awareness.

In this chapter, we will try to describe how a specific society – in this case, the state of Israel – has tried to address the social phenomenon of elder abuse and neglect. Specifically, we will try to describe how legislation and social services were developed and transformed throughout the years, in an attempt to combat and prevent its existence. While local and specific, the Israeli experience can have much broader lessons on the limitations of law and social policy as tools for social change, and on future directions for actions that are still needed.

4.2 Israeli Society

Israeli society is a multi-cultural, pluralistic society that includes a variety of national, religious, and ethnic groups. It has a strong traditional and family-oriented culture which mixes the Jewish majority's traditions and religious values with those of the country's Muslim, Christian, and Druze minorities (groups that constitute about 25% of Israel's population) (Brodsky et al. 2016). Israel is also an urbanized welfare state. Its welfare policies and legislation are shaped by a mixture of governmental and market forces, all of which impact elder abuse and neglect.

In Israel, as elsewhere in the modern world, society is undergoing a process of population ageing. The 2016 census shows that the aged (65+) comprise about 12% of the total population (Central Bureau of Statistics (CBS) 2016). In Israel currently, life expectancy is high: 84.6 for women and 81.2 for men (CBS 2016). The Israeli population is expected to continue to age, and it is forecasted that by 2025 the proportion of old people will reach 14%. In addition, there will be a further increase in life expectancy and the birthrate will continue to decline (Brodsky et al. 2016). Currently, the 75+ age group is close to 45% of the older population, and 87% of them are community dwellers (CBS 2016). This age cohort is the most vulnerable and can suffer from limitations in daily functioning and chronic diseases. Close to 14% of community dwelling elders report a disability or activities of daily living (ADL) difficulties. The percentage is higher among new immigrants (close to 17%) and even higher among non-Jews, nearing 30% (CBS 2016). This is congruent with data from the United States, indicating that socio-cultural factors are related to the incidence of chronic disease among older adults. This portion of the population needs closer care and assistance, which is still mostly provided by family members. Since older persons usually prefer aging at home – aging in place – the expectation is that needed care will be provided by the informal system – the familial system, usually adult children.

Studies show that family members provide most of the care for disabled elders (Lowenstein and Katz 2010; Lowenstein 2003). Thus, elder care can be a stressor

and even a source of conflict in family relations. The physical, emotional and economic burden of caring for an elder family member presents a growing challenge to societal priorities regarding elders and their families.

The traditional family values in Israel created for some decades a wrong picture of "elder abuse free society" until the late 1990s (Lowenstein and Ron 2000; Lowenstein 2003; Lowenstein and Doron 2013). Then, the study of elder abuse and neglect became visible in Israel especially after the First National Survey among 1045 community dwelling elders, Jews and Arabs, was conducted (Lowenstein et al. 2009). Its findings were presented at the President of Israel chambers and at the Health and Welfare Committee of the Israeli Parliament.

The survey provided the first National Database regarding the phenomena. Relatively, a high proportion of abuse and neglect was detected – 18.4% among older persons who reported that they had been exposed to one or more types of harm during the year prior to the survey. The findings were higher compared to other surveys conducted at that time (e.g. Pavlik et al. 2001; WHO 2011; Yan and Tang 2001; NCPOP 2012). It is probably because of an elder abuse and neglect broad definition as well as using a multitude of survey tools (Lowenstein and Doron 2013).

A low proportion of physical and sexual abuse was reported (2.3%) which is similar to findings in other countries. It may be related to the fact that physical and sexual abuse are usually combined with other abuse types. However, these rates were quite high among Arab women which corresponds to findings from other countries like studies conducted in People's Republic of China (Dong and Simon 2010) and India (Chokkanathan and Lee 2005; Sebastian and Sekher 2011). Financial abuse rates in the survey were 6.6%, verbal abuse 16%, most of it combined with other abuse types and 17% reported that they had experienced neglect (Lowenstein et al. 2009). The survey results indicated that elder abuse and neglect are a social and health issue related to human rights and social solidarity.

Since then, Israel has undergone a dynamic transition and change regarding elder abuse and neglect in varied areas – research, policy, legislation and social interventions. The elder abuse and neglect phenomenon had moved to the forefront of public, professional and political awareness (Lowenstein and Doron 2013).

4.3 Policy, Legislation and Service Developments

Elder abuse can only be effectively prevented by action at the appropriate national level. Such national plans were already developed in Ireland in 2002, the Check Republic in 2013 and in Singapore in 2016. Thus, after a variety of innovative legislative acts and service developments which were already in place, and will be described below, it was understood that to combat abuse, policy action in the form of a National Action Plan must be drawn up. Such a plan should include general guidelines and relevant legal bases to be established.

Currently, the Israeli Gerontological Society, headed by Prof. Y. Brick, with the involvement of several members, including Prof. Lowenstein, prepared *A National Plan for Care of the Older Population*, relating to the major issues in the field of

aging, including elder abuse and neglect. A special Parliamentary Committee had been established, headed by the vice-chair of the Israeli Parliament. This Committee meets bi-weekly and discusses the various topics of the plan. In the area of elder abuse and neglect, the following areas were suggested:

1. Prevention: This is through expansion of the work of the Special Units, which were established within most Municipal Welfare Departments to tackle elder abuse and neglect (it was one of the outcomes of the National Survey). Such work should include providing more help to family carers, identifying populations at risk and publishing more newspaper articles on the topic and increasing public awareness.
2. Identification: Emphasizing the role of family physicians, nurses and social workers and those working at hospital admission units, as well as community workers in special Elders' Clubs and Day Care Centers to identify elder abuse. It could be accomplished through more specific training on the topic, exposing the professionals to new data.
3. Intervention and Treatment: Providing on-going training to professionals working especially within the Health and Welfare systems. This could be achieved by special courses and workshops, developing training materials, using tools developed in this area like some of the NICE – National Initiative for Care of the Elderly (University of Toronto, headed by Prof. Lynn McDonald) pocket tools and others such as the EASI instrument developed by Prof. Mark Yaffe et al. (2008) in Canada.

4.4 Developments Within the Health and Welfare Systems in Israel

As older persons consume health and medical services in a relatively higher proportion and frequency than other age groups, it puts the health system's professionals, and especially family physicians and those in the admission units in hospital settings, in a situation where their accessibility to this population is high. The health system is, thus, one of the main gatekeepers, regarding prevention and treatment. Previous studies show that abuse rates among hospitalized elders are higher than in the general population. The reason may be due to extensive examinations that help in identification of abuse cases (e.g., Cohen et al. 2007).

The system in Israel focused on data dissemination among medical institutes to identify elder abuse cases. In addition to primary legislation – which will be described in detail below – a series of internal directives issued by the Director-General of the Ministry of Health has been published in 2003–2005. These directives deal with identifying victims of domestic violence (General Manager Circular 22/2003). Other circulars state that the aim is to "Broaden and deepen identification of and care for the aging population, from the moment suspicious is aroused…" (Clause 2.3). The circular obligates each health system – especially big hospitals – to establish Violence Committees, led by a senior physician and a senior social worker, who are responsible

for receiving reports, first from the Admission Units and from the various hospital departments, if abuse was detected. These reports should be forwarded to relevant agencies (welfare services, police and/or Health Ministry) as cited:

> …the committee's roles are: to supervise, monitor, and accompany the abuse cases' or apprehension for abuse cases' treatment. To implement the circular directives including reporting and recommendations of operational options to management according to changing needs (General Manager Circular, 22/2003).

Paragraphs 8–10 in the circular are dealing with treatment methods in each abuse or apprehension for abuse cases, in defending the victim during hospitalization and in action taken during hospital discharge. This includes establishing a continuum of care with relevant community welfare and social services. Paragraph 11 in the circular obliges each committee member to report on cases he/she had encountered. Therefore, there is a need for multi-disciplinary team collaboration in the process of identification of elder abuse and neglect and maintaining a continuum of care between hospitals that older victims' visit and the community (sick funds – HMO's, welfare services and the police).

The Welfare Ministry, after understanding the issue emanating from the results of the National Survey, decided to create Special Units with the different Welfare Departments at the municipal level. These units are operating as multi-system units working on the development of close relations with other services like community health clinics (HMO's), hospitals, elders' organizations, the police and the legal system to create continuity of care.

The units provide direct interventions to abusers and victims, raise public awareness, and support all professionals who work within the area of the respected municipality. The social workers in these units try to detect abuse cases, provide information to elders regarding their rights and the services available. In parallel, staff work with caregiving family members, providing them with knowledge and treatment abilities and informing them about existing rights and services. The units are also involved in community activity: providing information intended to increase awareness among elderly, professionals and the public. During the year 2015, more than 5000 elders suffering from abuse and neglect around the country were identified and treated by the existing 62 special units (Ministry of Welfare-Alon and Yuz 2015).

4.5 Legislative Developments

4.5.1 The Legislative Developments Prior to the 2016 Guardianship Law Reform

Israel has a rich history of legislative attempts to address the phenomena of elder abuse and neglect. This legal history has been described elsewhere (Doron et al. 2005; Lowenstein and Doron 2008, 2013) and can be summarized as a "legislative-generational" developmental process.

The first legislative generation of Israeli laws were enacted during the 1950s and 1960s, Typical examples included Israel's Legal Capacity and Guardianship Law of 1962; or the Defense of Protected Persons Law, of 1966. These laws did not view elder abuse and neglect as a specific or unique social phenomena but part of a broader social phenomena of social deviance or of helpless populations. As a result, this legislation "bundled" up older people in the same legal framework of various other "protected" populations such as children, persons with cognitive disabilities, mentally ill, or drug addicts. These laws commonly provided legal authorities via local social welfare officers, to intervene in the lives of older persons who were not able to care for themselves or were subject to abuse or neglect. Such typical interventions included either forced hospitalization, or placement under formal guardianship.

The second legislative generation in the field, which characterized the 1980s, continued to ignore the uniqueness of elder abuse and neglect. However, it reflected a sense of failure of social welfare authorities to efficiently combat cases of abuse of weak or frail populations. The outcome was a new wave of legislation which adopted this time a more criminal legal approach: preventing, deterring and punishing via the criminal justice system. The outcome was a major addition (Amendment No. 26, 1989) to Israel's Criminal Law of 1977, which for the first time incorporated a specific reference to abuse and neglect of minors and "helpless persons" (older persons being viewed as part of this group), in its various forms (physical, mental, and sexual), and defined it as a unique criminal offence. Moreover, the new criminal legislation introduced, for the first time, a very broad mandatory reporting mechanism, mandating not only professionals, but any person with reasonable suspicion of elder abuse, to report it either to the police or welfare officers.

The third wave of legislative development continued with the lack of specific reference to elder abuse as such, but tried to address this phenomena via a new broad legal approach: family violence laws. Stemming from feminist and women's rights' perspectives, Israeli law tried in the early 1990s, to adopt a new approach to address intimate and family violence. This approach recognized the failure of "traditional" criminal and social law approaches and tried to adopt a legal ideology which empowered the victims (mostly women) by handing them the power to initiate protective legal proceedings, without being dependent on police or welfare officers.

The most important outcome was the enactment of Israel's Prevention of Violence in the Family Law of 1991, which for the first time authorized victims of family violence to access Family Courts in an independent manner, in order to receive protective orders against their predators. Furthermore, it authorized the courts to issue treatment orders and have both sides engage in mediation and other alternative dispute resolution mechanisms as part of the legal process.

The fourth and final wave of legislative development in Israel, prior to the recent guardianship law reform, was held in the early 2000s. As described above, it was only in the 1990s and early 2000s that Israeli society was exposed to the phenomena of elder abuse and neglect – as a distinct social challenge. The combination of both the ground breaking empirical findings of Lowenstein (1998) along with the first national report and policy recommendations in the field (Eshel 2001) triggered a range of specific legal reactions. These new statutory developments were for the

Table 4.1 The generational development of Israeli legislation

	Time	Rationale	Legal Foci of Power	Statutory Example	Elder Specific?
Gen. 1	1950s–1960s	Social control and protection of helpless populations	Social welfare officers	Legal Capacity and Guardianship Law 1962	No – Part of "helpless populations"
Gen. 2	1980s	Deterring and punishing + reporting	Police/ criminal justice	Criminal law (amendment), 1989	No – Part of "helpless populations"
Gen. 3	1990s	Removal and treatment	The victims	Prevention of Family Violence Law 1991	No – Part of victims of family violence
Gen. 4	2000s	Mix: Awareness, early detection; social intervention; criminal deterrence;	Mix: Older persons and professionals	Ministry of Health Directives 2003–5	Yes

first time specifically and directly targeted at elder abuse and neglect, as such, and not as part of a broader law reform or bundled up with other protected populations.

One example of this new specific and direct response was the series of obligatory regulatory directives issued by the Ministry of Health, which were described in detail above. Another example of this new wave of direct and specific reform was an amendment to Israel's criminal code, not in the general context of abuse and neglect of "helpless" persons as a whole, but rather in defining a new specific criminal offence of battery of an older person along with providing a more severe punishment on such an offence compared to battery of a person which is not an older person.

To conclude, it could be argued that until the very recent major law reform of 2016, which will be described further below, the overall legislative developments in the field of elder abuse and neglect in Israel could be described as follows (Table 4.1):

It should be noted that these legislative shifts and "generational" developments were not unique to Israel. Various countries around the world have reformed their laws or enacted new pieces of legislations in order to address the newly exposed reality of elder abuse and neglect (e.g. Montegomery et al. 2016). Moreover, similar to the Israeli case, critics and concerns were raised in various jurisdictions with regards to the merits and success of these reforms to actually make a difference and promote the rights of older persons (e.g. Kohn 2012).

4.6 Israel's 2016 Guardianship Law Reform

In the last 3 years, a significant development has occurred in Israeli legislation which relates to the field of elder abuse and neglect: a major law reform in the field of adult guardianship (Kanter and Tolub 2017). Historically, Israel's Legal Capacity and Guardianship Law of 1962 has been under ongoing criticism for being over

paternalistic, ageist, and harmful in allowing, too easily, to strip older persons from their legal rights, under the guise of protection and care (Doron 2004). Therefore, and after years of political struggle, the Israeli Parliament, enacted a major law reform which will be described hereby.

Three main elements were included in this law reform:

4.6.1 The Establishment of a Supportive Decision Making Mechanism as an Alternative to Formal Guardianship

Until the recent law reform, the typical legal approach in Israel towards legal capacity was a binary approach: either the person had legal capacity – which meant he or she were fully autonomous and capable of all legal actions; or did not have legal capacity – which meant that he or she needed a formal guardian to provide substitute decision-making, based on the best interests of the person. The outcome was that for many older persons, even in early stages of mental disability (e.g. the beginning of dementia), or even of physical disability (e.g. the inability to move independently), being placed under total guardianship while losing all independent legal status was very easily done (Doron 2004).

It was actually Israel's signing and ratifying the International Convention for the Rights of Persons with Disabilities (CRPD) (UN 2006), which triggered the public discussions around the need to develop supportive mechanisms which will allow older persons (and others) to maintain their independence, autonomy, and legal capacity, even in cases of disability. The disability rights movement raised the awareness that support systems can empower and enable older persons to maintain their ability to control their lives and have their wishes voiced and honored (Kanter 2009). The outcome was that for the first time, Israel law formally recognized the legal ability to have a "supportive decision maker" as an alternative to formal guardianship, which mirrored a broader socio-legal shift moving away from guardianship to supported decision-making (Diller 2016).

4.6.2 The Establishment of Continuing Power of Attorney for Property and Personal Care as an Alternative to Formal Guardianship

Prior to the recent law reform, very few legal alternatives existed with regards to older persons who were starting to lose their mental capacity or were having difficulties in managing their affairs due to physical or mental dependence. Moreover, research indicated that even the very limited existing alternative which did exist was mostly unknown or not used (Doron and Gal 2006). As part of the recent law reform,

a newly established legal mechanism was adopted – a continuing power of attorney – enabling capable adults to nominate an agent to be their power of attorney in cases future incapacity. Such binding legal documents can not only prevent the need for formal guardianship, but can also secure that the personal preferences and wishes will be respected and honored.

4.6.3 Reforming Existing Guardianship Regime as to Minimize Its Scope, and Transforming It to an Option of Last Resort

The third major element of the recent law reform addressed some of the weaknesses that existed in the "traditional" guardianship system. The changes made reflected the shift in social values and in the need to improve procedural justice. For example, it is now mandated under the newly reformed law, that formal guardianship will be only a tool of last resort and be requested only after all other less restrictive legal alternatives have been exhausted. Moreover, the burden of proof is on the side who asks for guardianship to show that no other less restrictive alternatives were available. The standard of decision making and the view point of the guardianship has also shifted form an "objective" best-interest criteria, to a subjective, personal preferences criteria, mandating guardians to make all efforts to gather and reflect in their actions, the personal values and preferences of the person under guardianship.

Overall, the 2016 guardianship law reform was much more than a simple law reform. It reflected a major shift in Israel's policy from an ideology focused mostly on protection and paternalistic intervention in the lives of older persons to an ideology which is founded on respecting autonomy, personal freedom, and the recognition for the need of support (and substitution) in order to secure them (Kanter and Tolub 2017). While it was not a direct and specific reform in the field of elder abuse and neglect, it certainly sent an ideological "message" in that field as well. The message is that Israeli society needs to focus its efforts to intervening before cases of abuse and neglect have been identified. The efforts need to be focused in prevention, support and empowerment, enabling older people, despite natural decline or new disabilities, to continue to be independent, and have their wishes and preferences honored, hence securing and preventing the ability to abuse or neglect them.

4.7 Conclusion

To sum up, we have demonstrated that research and a national database can impact policy, service developments and legislation. During the last two decades Israel made advanced strides in combating elder abuse and neglect. However, we should

continue this work and explore and develop additional intervention and prevention services and devise more innovative care models. An integrative approach is needed to coordinate the work and create partnerships between the criminal-legal system and the health-welfare systems.

It is also important to work on translating successful policies and initiatives into new contexts as suggested by the *National Plan for Care of Elders* to contribute to increasing awareness of elder abuse and neglect and to create sustainable action to eradicate it. More collaboration should be advanced to allow systematic information exchanges and alliance among all involved in elder care. We have to continue to raise public and professional awareness on elder abuse and neglect.

Advances in our understanding of the many manifestations of elder abuse and the emergence and development of inter-professional-team approaches shows the important strides Israel has made in coping with elder abuse and neglect.

From a legislative reform perspective, Israel's experience has seen some significant developments and transformation. The historical trend was a shift from an emphasis on social welfare legislation targeting "helpless" populations, to a criminal justice approach along with mandatory reporting, to a more gendered prevention of family violence model. All these developments were not "elder abuse" specific, but covered the field in practice. It was only in the early 2000s, that elder abuse and neglect, as a unique and specific phenomenon, received a more direct and specific legislative and statutory considerations, which was very diverse in its actual content.

However, the legislative action in this field received a major shift as part of the recent adult guardianship law reform. While not "elder abuse" specific, this new and significant reform reflected a much deeper change in ideology and social values which indirectly affect the legal policies in the field of elder abuse and neglect. Echoing the CRPD (U.N. 2006), the changes in legislation, the restriction and minimalization of "traditional" guardianship, along with the establishment and promotion of both advance legal planning, and more importantly, supportive decision-making mechanisms, mirrored the focus of enabling independence, and combating abuse and neglect by empowering the older population via supportive services, and through a new social construction of vulnerability and dependency.

As this reform is very new, and as the whole concept of supportive decision-making is in its infancy, it is yet to be seen to what extent it is actually successful in preventing or reducing elder abuse and neglect. While there is little experience with supportive decision-making, other countries' experience with continuing powers of attorney show that while they may empower and prevent unnecessary guardianship, they may by themselves be tools for abuse and exploitation (Rhein 2009). Hence, it is time to see the effects of Israel's most recent law reform on the reality of elder abuse and neglect.

In light of the above picture, some recommendations for future action and research can be provided:

4.8 Need for Empirical Legal Studies to "Measure" and Assess the Impact of Legislation

Quite surprisingly, despite the wealth of legal changes and developments in Israel, there is very little empirical or evaluative research which attempts to measure and assess the degree of success or failure of the laws which attempt to make a difference in the field of elder abuse and neglect. For example, very little is known about the success or failure of the 1989 legislative amendment which added the mandatory legal requirement to report cases of elder abuse and neglect. There are those who question the efficiency and ability of such reporting laws to be effective in the field of elder abuse and neglect (e.g. see Doron et al. 2013, Kohn 2012). Without evidence based legal practice, it is still a big question to what extent legislation alone and which kind of legislation, specifically, can actually make a difference in the field.

4.9 The Need to Address Legal and Normative Gaps

Despite the rich legal developments which were described above, there are still some existing legal gaps within Israeli legislation. For example, the field of financial abuse and exploitation was and still is missing a direct and specific reference under existing law. More specifically, a recent study in the field of elder consumer fraud has shown how existing consumer protection law in Israel fails to fully address the unique challenges faced by older consumers. Hence, a specific effort should be given at identifying existing normative gaps, while providing tailored legislative responds (Segal et al. under review).

4.10 Allotment of Resources and Provision of Services

Finally, while it has been raised in the past (e.g. Doron et al. 2005), it is still relevant to re-emphasize the issue of the need to allocate public financial resources alongside the legislative reform process. A financial analysis of the legislation pertaining to elder abuse and neglect in Israel shows that most of the statutes do not require resources to be allotted specifically to deal with this issue. The applications of the relevant laws, particularly those of the first three generations, rely on existing general, financial and institutional systems and comprehensive budgets. For example, welfare officers for the court who deal in general with older people, are employed by local municipalities. Their responsibilities to deal specifically with elder abuse and neglect must be undertaken over and above their other responsibilities as social workers caring for the aged; this is unlike welfare officers for the court dealing with children or women at risk, who receive extra funding for these legal responsibilities.

Even the most recent 2016 guardianship law reform did not include any new financial support. On the contrary, its goal was to reduce formal guardianship, alongside increasing "privately-based" alternatives in the form of continuing powers of attorney, or privately funded supported decision makers.

The unwillingness to allocate significant financial resources to fund social services for older people may stem from the fact that they are not a politically strong social group. Furthermore, any money allocated to help the aged, would therefore have to be found at the expense of other, politically stronger, groups (Pearson and Richardson 1993). Nonetheless, it must be recognized that progress in the struggle against elder abuse can only be made if the law requires the allocation of resources**.**

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Chapter 5
Elder Abuse Policy, Past, Present, and Future Trends

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5.1 Introduction

The history of policy related to elder abuse spans more than 50 years and reflects an evolving understanding by policymakers and the general public that rather than being a private sphere, family matter problem, elder abuse is a public sphere problem. In fact, it is an issue of national import, touching such sectors as social services, healthcare, law enforcement, and banking. As a social justice issue, societal recognition of and action concerning elder abuse has been both protracted and circuitous. Although elder abuse dates back to the beginning of human history, the problem has gained traction relatively recently. Given the attention paid to child abuse and intimate partner violence against women, the historical lack of political will to take action to prevent and punish elder abuse is surprising (Teaster et al. 2010).

In the chapter that follows, we consider examples of federal elder abuse policy in the United States as well as major international initiatives. Our treatment reflects changing societal conceptions of aging, social justice, and recognition of the problem of elder abuse as one encompassing human rights.

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5.2 Major National Efforts to Address Elder Abuse in the United States

The genesis of United States (US) policy on elder abuse dates to the 1950s when the Department of Health, Education, and Welfare awarded grants for "protective service unit "demonstration projects" (Blenkner et al. 1971). The 1961 White House Conference on Aging (WHCoA) was also instrumental in highlighting this problem (Dubble 2006). In 1962, Public Welfare Amendments to the Social Security Act authorized payments targeted to states for establishing protective services and funding demonstration projects. The passage of the 1965 Older Americans Act (OAA) increased awareness and advocacy concerning the needs and rights of older adults. Though the OAA helped states develop programs to assist older adults in its early iterations, it did not specifically mention elder abuse. However, these two pieces of federal legislation encouraged states to enact laws and protective services for older adults (Dubble 2006).

In the 1970s and 1980s, progress as well as setbacks continued related to bringing elder abuse into the fore of public consciousness. In 1971, the White House hosted a second WHCoA. In 1974, the Social Security Act authorized Adult Protective Services (APS) under Title XX, stimulating some states to create APS units and to mandate reporting of elder abuse. In 1981, Title XX was converted to the Social Services Block Grant (SSBG) with the unfortunate consequence of under-resourcing sorely needed APS programs (Lynch 2016). Also in 1981, a third WHCoA included the issue of elder abuse, and in the same year, the US House of Representatives Select Committee on Aging produced a nationally galvanizing report entitled *Elder Abuse: An Examination of a Hidden Problem* (Teaster et al. 2010).

In 1984, Congress passed the Victims of Crime Act (VOCA), which provided financial compensation to victims to cover costs caused by being a victim of crime, including health care and lost wages. Though applicable to all ages of crime victims, VOCA improved services to victims of elder abuse and established the Crime Victims Fund, which earmarked some funds to deal with elder abuse (Crime Victims Fund 2017; National Association n.d.; Office of Victims of Crime n.d.).

In 1985, acting in his capacity as Chairman of the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging, US Representative Claude Pepper of Florida, a champion of older adults for more than a decade, issued a stunning report, *Elder Abuse: A National Disgrace,* which caught public attention and inspired political action. In 1987, Congress passed the Omnibus Budget Reconciliation Act (OBRA), requiring that nursing homes protect and preserve the quality of life of residents. Regulations emanating from OBRA specifically defined elder abuse in the context of long-term care (LTC) facilities, mandated states' responsibility to investigate abuse allegations against facilities, and required LTC facilities to train staff on elder abuse prevention (Teaster et al. 2010). Also in 1987, the reauthorization of the OAA defined and required that Elder Abuse Prevention Services incorporate public education and identification of abuse and create

mechanisms to receive reports of abuse (Dubble 2006; Teaster et al. 2010). The 1987 reauthorization also strengthened LTC Ombudsman Programs so that they could better deal with abuses in US nursing homes.

In 1990, Congress provided funding earmarked for elder abuse prevention–$2.9 million divided among 50 states, the District of Columbia, and the US Territories. According to the National Adult Protective Services Association (2016), states were spending an average of $45.03 per child and only $3.80 per adult on protective services.' Although the funding was inadequate, the Administration on Aging (AoA) provided the scaffolding for continued action. In 1988, the AoA created the National Center on Elder Abuse (NCEA), made permanent in the 1992 reauthorization of the OAA. Title VII included Allotments for Vulnerable Elder Rights Protection Activities: the Long-Term Care Ombudsman Program, Programs for the Prevention of Abuse and Exploitation, and State Legal Assistance Development Programs (Lindberg et al. 2011). About the same time, the House Select Committee on Aging's Subcommittee on Health and Long-Term Care issued *Elder Abuse: A Decade of Shame and Inaction* (1990) and *Protecting America's Abused Elderly: The Need for Congressional Action* (1991). In 1992, The Family Violence Prevention Services Act funded the National Elder Abuse Incidence Study (NEAIS), conducted by the Administration for Children and Families and AoA, data from which helped support assertions that many cases of elder abuse were reported to APS and/or local authorities (Dubble 2006). In 1995, then President Clinton announced the fourth WHCOA. Under the leadership of Executive Director Robert Blancato, the 1995 WHCoA devoted unprecedented attention to elder abuse, passing two resolutions dedicated solely to the protection of vulnerable older adults (WHCOA 2015, 2016).

5.3 Passage (Finally) of the Elder Justice Act

In 2010, the Elder Justice Act (EJA) became law as part of the Patient Protection and Affordable Care Act (ACA). Representing a decade of effort by advocates and policymakers, the EJA was the first federal law to state that 'it is the right of older adults to be free of abuse, neglect, and exploitation' (Teaster et al. 2010). The EJA established an Elder Justice Coordinating Council (EJCC) made up of designees of the Secretary of Health and Human Services (HHS), the Attorney General of the Department of Justice, and other federal agencies to foster coordination on elder abuse throughout the federal government. Supplementing the EJCC is a 27-member Advisory Board appointed by the Secretary and made up of diverse experts on elder abuse, neglect, and exploitation. Unfortunately, membership for the Advisory Board has never been appointed. To enhance uniformity for research on elder abuse protections, the EJA requires the Secretary to promulgate regulations guiding researchers (EJA 2014).

Establishing Forensic Centers Section 2031 (42 U.S.C. 1397 l) authorizes ten centers to develop forensic expertise pertaining to elder abuse, neglect, and

exploitation; provide services in local communities, and make data available to develop the capacity of geriatric health care professionals and law enforcement to collect forensic evidence. Congress has not yet appropriated funding for this purpose.

Strengthening Adult Protective Services Section 2042 (42 U.S.C. 1397 m-1.) requires the Secretary of HHS to:

1. Provide funding to state and local APS offices as well as funding for demonstration programs by state and municipal governments for training in methods of detection or prevention.
2. Coordinate with the Department of Justice to collect and disseminate annual data relating to the abuse, neglect, and exploitation of elders.
3. Develop and disseminate information and conduct training on best practices in carrying out APS.
4. Conduct research related to the quality of APS programs.
5. Provide technical assistance to states and other entities that provide APS.

Congress has provided limited funding in addition to HHS from the Prevention and Public Health Fund (PPHF) for elder justice activities. Six million dollars in PPHF funds were used for five state awards for Elder Abuse Prevention Intervention Programs. In Fiscal Year (FY) 2015, the Administration for Community Living (ACL) received a $4 million appropriation for demonstration grants to states to enhance their APS systems. With FY 2016 funds, the ACL announced funding opportunities under its Elder Justice Innovation Grants program, which included the areas of self-neglect, abuse in guardianship, elder abuse forensic centers, and elder abuse in Indian Country.

Enhancing the Capacity of Long-Term Care Settings Section 2041 (42U.S.C. 1397 m) requires the Secretary of HHS, in coordination with the Secretary of Labor, to provide grants to LTC facilities and community-based long-term care entities to create incentives for direct care workers to seek, train for, and maintain employment in long-term care facilities. The Secretary must adopt electronic standards for the exchange of clinical data by LTC facilities and develop procedures to accept electronic submission of clinical data.

Section 2043 (42U.S.C. 1397 m-2) provides grants to improve the capacity of long-term care ombudsmen to respond to elder abuse and neglect, conduct pilot programs, and provide support. Section 2046 combines a number of mandates to accomplish the above objectives:

- Create a National Training Institute (42 U.S.C. 13951-3a) to provide and improve the training of surveyors to investigate allegations of abuse and neglect and misappropriation of property in programs and facilities that receive payments under Medicare or Medicaid.
- Require LTC facilities to report a crime or the reasonable suspicion of a criminal act against a resident to law enforcement within 2 h in the case of serious bodily

injury, or otherwise within 24 h (42 U.S.C. 1320b-25). Failure to comply with this regulation or retaliation against any reporter will trigger substantial civil monetary penalties.
- Require the Secretary to study the need to establish a national nurse aide registry and to report its findings to the EJCC and specified congressional committees by September 2011 (EJA 2014).

Finally, two related provisions in the ACA not technically part of the EJA deserve mention. Section 6121 amends initial training requirements for nursing facility staff to include training in dementia management and patient abuse prevention. Section 6201 requires the Secretary of HHS to establish a program to identify efficient, effective, and economical procedures for long-term care facilities to conduct background checks on prospective direct patient access employees on a nationwide basis. Despite an underwhelming pattern of implementation and funding, there have been a number of notable activities:

1. A grant by the ACL to provide a National APS Resource Center from 2011 to 2015.
2. A two-year pilot by ACL and the HHS Office of the Assistant Secretary for Planning and Evaluation to design and test a National Adult Mistreatment Reporting System.
3. Elder Abuse Prevention Intervention Grants made by ACL in FY 2012 – FY 2015. The project evaluated replicable best practices in support of the development of secondary and tertiary prevention and intervention strategies. Using the results, AoA/ACL developed a resource for APS programs to use to improve their programs.
4. AoA/ACL, in collaboration with Substance Abuse and Mental Health Services Administration (SAMHSA), Centers for Disease Control (CDC), and the National Institutes of Health/National Institution on Aging (NIH/NIA) to incorporate elder abuse screening into the CMS proposed rule on annual wellness visits.
5. In 2013, CMS convened an Elder Mistreatment Symposium to revise existing elder abuse measures and to make recommendations for elder abuse screening, screening tools, and protocols for handling suspicions of elder abuse.
6. The Department of Justice's Elder Justice Initiative (EJI) established the Elder Justice Website as a resource for elder abuse prosecutors, researchers, practitioners, and for victims of elder abuse and their families, as well as a forum for law enforcement and elder justice policy communities to share information and enhance public awareness on the subject matter. Also, the EJI collaborated with DOJ's Access to Justice Initiative and the Office of Victims of Crime to support the development of online training for legal aid offices to detect and address elder abuse, neglect, and exploitation.
7. In July 2014, the Federal Trade Commission launched a new fraud education campaign aimed at older people. The 'Pass It On' campaign is based on the theory that older adults have agency and thus are part of the solution, not simply the victims of scammers.

8. DOJ, with support from ACL, created the Elder Justice Roadmap to set priorities advancing elder justice by collecting information from 750 US stakeholders.

Going forward, sustained advocacy is crucial for the implementation of the EJCC's recommendations and continued action by federal government agencies. Perhaps the most pressing task for advocates is to work with congressional supporters to pass legislation reauthorizing the EJA (Lindberg et al. 2011).

In the 115th Congress and the 116th Congress, there continues to be positive momentum in the work to end elder abuse, neglect, and exploitation. The following are some of the efforts.

5.4 Elder Abuse Prevention and Prosecution Act of 2017

Passage and signing of the bipartisan Elder Abuse Prevention and Prosecution Act of 2017 in October 2018 was a major milestone in the fight against elder abuse, particularly elder financial exploitation. This new law (P.L. 115-69 – S. 178) enhances the federal government's response to elder abuse and financial exploitation by sending a strong message that the Department of Justice will search for and prosecute criminals to the full extent of the law. The bill was sponsored by Senate Judiciary Committee Chairman Chuck Grassley (R-IA) and Sen. Richard Blumenthal (D-CT), two long-time advocates for the rights of older adults.

Here are the provisions of the law from the Congressional Research Service:

5.4.1 Title I–Supporting Federal Cases Involving Elder Justice

(Sec. 101) This bill establishes requirements for the Department of Justice (DOJ) with respect to investigating and prosecuting elder abuse crimes and enforcing elder abuse laws. Specifically, DOJ must:

- designate Elder Justice Coordinators in federal judicial districts and at DOJ,
- implement comprehensive training for Federal Bureau of Investigation agents, and
- establish a working group to provide policy advice.

The Executive Office for United States Attorneys must operate a resource group to assist prosecutors in pursuing elder abuse cases.

The Federal Trade Commission must designate an Elder Justice Coordinator within its Bureau of Consumer Protection.

5.4.2 Title II–Improved Data Collection and Federal Coordination

(Sec. 201) DOJ must establish best practices for data collection on elder abuse.

(Sec. 202) DOJ must collect and publish data on elder abuse cases and investigations. The HHS must provide for publication data on elder abuse cases referred to APS.

5.4.3 Title III–Enhanced Victim Assistance to Elder Abuse Survivors

(Sec. 301) This section expresses the sense of the Senate that: (1) elder abuse involves exploitation of potentially vulnerable individuals; (2) combatting elder abuse requires support for victims and prevention; and (3) the Senate supports a multipronged approach to prevent elder abuse, protect victims, and prosecute perpetrators of elder abuse crimes.

(Sec. 302) DOJ's Office for Victims of Crime (OVC n.d.) must report to Congress on the nature, extent, and amount of funding under the Victims of Crime Act of 1984 for older adult victims of crime.

5.4.4 Title IV–Robert MATAVA Elder Abuse Prosecution act of 2017

Robert Matava Elder Abuse Prosecution Act of 2017 (Robert Matava experienced financial exploitation in Connecticut.)

This bill amends the federal criminal code to expand prohibited telemarketing fraud to include 'telemarketing or e-mail marketing' fraud. It expands the definition of telemarketing or e-mail marketing to include measures to induce investment for financial profit, participation in a business opportunity, or commitment to a loan.

A defendant convicted of telemarketing or e-mail marketing fraud that targets or victimizes a person over age 55 is subject to an enhanced criminal penalty and mandatory forfeiture.

The bill adds health care fraud to the list of fraud offenses subject to enhanced penalties.

(Sec. 403) DOJ, in coordination with the EJCC, must provide information, training, and technical assistance to help states and local governments investigate, prosecute, prevent, and mitigate the impact of elder abuse, exploitation, and neglect.

(Sec. 404) It grants congressional consent to states to enter into cooperative agreements or compacts to promote and to enforce elder abuse laws. The State

Justice Institute must submit legislative proposals to Congress to facilitate such agreements and compacts.

5.4.5 Title V–Miscellaneous

(Sec. 501) This section amends Title XX (Block Grants to States for Social Services and Elder Justice) of the Social Security Act to specify that HHS may award APS demonstration grants to the highest courts of states to assess adult guardianship and conservatorship proceedings and to implement necessary changes. The highest court of a state that receives a demonstration grant must collaborate with the state's unit on aging and APS agency.

(Sec. 502) The Government Accountability Office (GAO) must review and report on elder justice programs and initiatives in the federal criminal justice system. The GAO must also report on: (1) federal government efforts to monitor the exploitation of older adults in global drug trafficking schemes and criminal enterprises, the incarceration of exploited older adults who are US citizens in foreign court systems, and the total number of elder abuse cases pending in the US; and (2) the results of federal government intervention with foreign officials on behalf of US citizens who are elder abuse victims in international criminal enterprises.

(Sec. 503) DOJ must report to Congress on its outreach to state and local law enforcement agencies on the process for collaborating with the federal government to investigate and prosecute interstate and international elder financial exploitation cases.

(Sec. 504) DOJ must publish model power of attorney legislation for the purpose of preventing elder abuse.

(Sec. 505) DOJ must publish best practices for improving guardianship proceedings and model legislation related to guardianship proceedings for the purpose of preventing elder abuse.

5.5 H.R.2639 – Elder Justice Reauthorization Act

Representatives Peter King (R-NY, 2nd) and Suzanne Bonamici (D-OR, 1st) introduced H.R. 2639 to reauthorize the EJA. The bill is considered a straight reauthorization of the previous law that has expired. Plans for reintroduction in the 116th Congress are underway in both the House and the Senate. King and Bonamici also announced the establishment of a bipartisan Elder Justice Caucus in the US House of Representatives. The caucus hopes to unify the elder justice voice in Congress by bringing together members with a shared interest in preventing elder abuse.

The Senior Safe Act, which became law as part of S.2155, is designed to prevent older adult financial abuse by providing immunities for reporting under bank privacy

laws. The bills were sponsored by Reps. Kyrsten Sinema and Bruce Poliquin and Sens. Susan Collins and Claire McCaskill.

H.R. 1457, the MOBILE Act, which also became law as part of S.2155, authorizes a national standard for banks to scan and retain information from driver's licenses and identity cards as part of a customer online onboarding process, via smartphone or website. The House version was sponsored by Reps. Scott Tipton and Terri Sewell, and the Senate version was sponsored by Senator Tim Scott.

The RAISE Family Caregivers Act, which became law as PL 115-119, directs HHS to develop and make publicly available a National Family Caregiving Strategy that identifies recommended actions for recognizing and supporting family caregivers, and creates a Family Caregiving Advisory Council to advise the department on recognizing and supporting family caregivers.

The Grandparents Raising Grandchildren Act, which became law as PL 115-196, establishing an Advisory Council to Support Grandparents Raising Grandchildren. The Council must identify, promote, coordinate, and publicly disseminate information and resources to help older relatives meet the needs of the children in their care and maintain their own health and emotional well-being.

The BOLD Act, which became law, amended the Public Health Service Act to award cooperative agreements: (1) for the establishment or support of national or regional centers of excellence in public health practice in Alzheimer's disease; (2) to state public health departments, Native American tribes, and other entities to promote cognitive functioning, address cognitive impairment and unique aspects of Alzheimer's disease, and help meet the needs of caregivers; and (3) for analysis and public reporting of data on the state and national levels regarding cognitive decline, caregiving, and health disparities, and monitoring of objectives on dementia and caregiving in the Department of Health and Human Services' Healthy People 2020 report.

Passage in the House (but not in the Senate) in the 115th Congress of authorization of the **Geriatric Workforce Enhancement Program** (GWEP) (S.2888, H.R.3713, H.R.3728) is a bipartisan bill that would prioritize funding for primary care geriatric workforce programs that integrate competencies of elder abuse.

H.R. 3728, the **Educating Medical Professionals and Optimizing Workforce Efficiency Readiness (EMPOWER) Act**, sponsored by Reps. Michael Burgess (TX), Jan Schakowsky (IL) and Larry Bucshon (IN), passed the House by voice vote but was not enacted into law.

- Introduced in the Senate and House was the **Stamp Out Elder Abuse Act**. Bill sponsors included Senators Susan Collins, Claire McCaskill, and Amy Klobuchar and Representatives Peter King, Carolyn Maloney, Suzanne Bonamici, and Jan Schakowsky. The bill would create a semi-postal stamp (also known as a 'charity stamp') to provide additional funding to the federal government for programs to address elder abuse, neglect, and exploitation. The bill sponsors have plans to re-introduce it in the 116th Congress.
- The Senate Special Committee on Aging has been working for more than a year on hearings, a report, and legislation to address the many problems that have

become well-known with guardianships. Senators Collins and Casey have introduced the **Guardianship Accountability Act of 2019**, which focuses on three key areas that should be addressed: oversight of guardians and guardianship arrangements, alternatives to guardianship and restoration of rights, and the need for better data.

5.6 Funding Challenges

The ongoing priority of advocacy groups like the Elder Justice Coalition is to secure appropriations for the programs that Congress has authorized through the EJA the Older Americans Act, SSBG, and other programs that help prevent or address elder abuse, neglect, and exploitation. To date, a total of $58 million in direct funding for EJA programs, such as the Elder Justice Initiative, has been secured.

- Congress gave the Elder Justice Initiative a $2 million increase for FY 2018, bringing it to a funding level of $12 million for FY 2018 and again in FY 2019.
- Other programs related to elder justice included $1.7 billion for the SSBG, $21.7 million for the Long-Term Care Ombudsman program (and elder abuse prevention in Title VII of the OAA), and $3.9 million for Elder Rights Support Activities
- At the December 6 meeting of the Elder Justice Coordinating Council, the DOJ, represented by Antoinette (Toni) Bacon, who serves as the National Elder Justice Coordinator and Associate Deputy Attorney General, announced that the DOJ is increasing resources to elder abuse victims. Their Office for Victims of Crime will provide nearly $18 million to help older adults who are victims of crime.
- Funding for 15 separate grant awards related to elder justice were also announced in the Fall of 2018 by ACL. One award is for the Orutsararmiut Native Council in Bethel, Alaska, for a two-year project that aims to reduce harm and maltreatment among Yup'ik Eskimo elders. Also, 14 states received grants to enhance statewide APS systems, evaluate and improve practices, and improve data collection and reporting to ACL's National Adult Maltreatment Reporting System.

These funds and programs are critically important to the older Americans they serve. Unfortunately, they only address a small number of the millions of older adults who are abused and exploited each year.

5.7 The Older Americans Act

The Older Americans Act (1965) (OAA) was the first federal law to provide comprehensive services for older adults without means testing. Its passage was a triumph for the new fields of gerontology and geriatrics. Based on a model of active aging (Atchley 1989), the OAA created the National Aging Network, composed of the AoA (incorporated in 2012 into the Administration for Community Living)

(federal level), State Units on Aging (state level), and Area Agencies on Aging (local level). Like many federal programs, the OAA must be continually reauthorized by Congress, and funding for it consistently fails to meet OAA aspirations and mandates. To address funding shortfalls, services are increasingly targeted to specific groups of older adults. In general, the OAA funds nutrition and supportive home and community-based services, disease prevention/health promotion services, training for employment, the National Family Caregiver Support Program and the Native American Caregiver Support Program, and elder rights programs (Title VII or the Vulnerable Elder Rights Protection Title). Title VII strengthens and coordinates the LTC Ombudsman (LTCO) Program; Programs for the Prevention of Abuse, Neglect and Exploitation; State Legal Assistance Development Programs; and Native American Organization and Elder Justice. Actually, all titles of the Act address elder abuse in one way or another (ACL 2017).

Since its establishment in the 1970s, the LTCO program has played a major role in identifying and addressing abuse, neglect, and exploitation of residents of nursing homes, board and care, and assisted living facilities. Long-term care ombudsmen advocate for residents of nursing homes, board and care homes, and assisted living facilities. The National Association of State Long-Term Care Ombudsman Programs (NASOP) has been advocating for several years for a $20 million appropriations specifically to support additional ombudsmen to address assisted living facilities quality concerns in particular. The total funding under Title VII for the LTCOP is only $17.784 million for FY 2019.

Ombudsmen educate consumers about making informed choices and how to get quality care as well as assist consumers with resolving complaints. Every state is required to have a LTCO program. In 2016, the program included the provision of services by 7331 volunteers certified to handle complaints and more than 1100 paid staff. For every one staff ombudsman, about six volunteer ombudsmen serve residents. In 2016, ombudsman staff and volunteers investigated 199,493 complaints made by 129,559 individuals. Ombudsmen were able to resolve or partially resolve 74% – or three out of every four complaints investigated. In January 2015, AoA published historic final federal regulations for the long-term care ombudsman (LTCO) program.

Also through the OAA, ACL supports the National Long-Term Care Ombudsman Resource Center and the National Center on Elder Abuse (NCEA), which subcontracts with partner organizations to implement its mission. The NCEA serves as a national resource center dedicated to the prevention of elder abuse. It offers a resource database of research and education and training materials related to elder abuse (ACL 2017).

5.8 Violence Against Women Act

In 1994, Congress passed the Violence Against Women Act (VAWA) in recognition of the severity of crimes associated with domestic violence, sexual assault, and stalking. Though criminal victimization of older women is generally declining (Office of Justice Programs 1994), older adults are less likely to report crime and more likely to sustain lasting (and sometimes fatal) injuries than their younger counterparts (DOJ 2019). The Office on Violence Against Women (OVW) was created to implement VAWA (Violence Against Women Act 2016). In 2002, legislation made the OVW a permanent part of the Department of Justice with a presidentially-appointed, senate-confirmed director. OVW administers financial and technical assistance to communities across the country that are developing programs, policies, and practices aimed at ending domestic violence, dating violence, sexual assault, and stalking. Currently, OVW administers 4 formula-based and 20 discretionary grant programs. The four formula programs include the following: STOP (Services, Training, Officers, Prosecutors), SASP (Sexual Assault Services Program), State Coalitions, and Tribal Coalitions. By forging state, local, and tribal partnerships among police, prosecutors, judges, victim advocates, health care providers, faith leaders, and others, OVW grant programs help provide victims with the necessary protections and services required for the pursuit of safe and healthy lives, while simultaneously enabling communities to hold offenders accountable for their violence. The section of the VAWA that addresses strengthening the health care system's response to domestic violence includes grants for elder abuse and the development of training modules and policies that address the overlap of elder abuse, domestic violence, child abuse, and other violence. With VAWA operating under current authorization, the main challenge for advocates is to press for adequate funding for implementation of its programs and to collaborate with providers of services to victims of domestic violence to ensure that they are equipped to meet the particular needs of victims of late-life domestic violence (Late Life Domestic Violence 2006).

5.9 Major International Efforts to Address Elder Abuse

While a number of notable accomplishments to address the issue of elder abuse have taken hold in the US, international efforts to address the problem are running somewhat parallel and sometimes, are more comprehensive. Rather than address the problem from the theoretical vantage of social work, medicine, or law, the problem is couched internationally as one of human rights.

5.10 Universal Declaration of Human Rights (1948)

The Universal Declaration of Human Rights (UDHR) is a landmark human rights document that resulted from the necessity to declare fundamental human rights in the wake of the atrocities occurring in the two world wars. The UDHR was drafted by individual representatives from diverse countries and cultures around the world and was ratified by the United Nations General Assembly in 1948; it was signed by 48 countries. Translated into more than 500 languages (the most translated document in the world), it proclaims fundamental human rights deserving universal protection (United Nations n.d.). Its preamble sets the stage for the individual declarations:

> Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world.

The UDHR contains 30 articles outlining fundamental human rights principles and the importance of nations to bind together to promote them.

> All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood. (Article 1).

Moreover, everyone has the right to life, liberty, and security of person (Article 3), should not be slaves (Article 4), and should not be subject to torture or inhuman punishment (Article 4). People should not be arbitrarily discriminated against (Article 8), imprisoned (Article 9) or moved, and should have due process in criminal proceedings (Articles 10–13). People have rights to their nationality and to free association (Articles 14–17). In addition, people have the right to have freedom of thought, expression, worship, and belief (Articles 18–20). Articles 21–24 declare the importance of involvement in government, resources, work, and equal pay for equal work. Articles 25–27 address the rights of individuals to be free from basic want (e.g., food, housing, shelter, medical care, social services) and to be educated. Finally, Articles 28–30 attest to the permanency and support that states should give to upholding the Articles and UDHR as a whole. The US is the only industrialized country that has failed to ratify the UDHR (United Nations n.d.).

5.11 United Nations Principles for Older Persons (1991)

The UN Principles for Older People were adopted by a UN General Assembly in 1991, undergirded by the recognition that older persons contribute to their societies and are reaching advanced age in greater and unprecedented numbers worldwide. Like the UDHR, the document emphasizes human rights, the worth and dignity of human persons, and the equality of men and women. In particular, the UN Principles include the broad categories of independence, participation, care, and self-fulfillment.

Under the category of independence, older adults should have access to adequate food, water, shelter, clothing and health care; the opportunity to work; to participate and choose when to exit the labour force; appropriate education and training programs, safe and adaptable living environments; and the ability to remain in their homes as long as possible. Under participation, older adults should remain integrated into society, have opportunities for service in the community, and be free to form movements or associations. Under the topic of care, older people should have family and community care in accordance with their society's culture, have access to health care, have access to social and legal services, be free to make use of appropriate levels of care in facilities, and enjoy human rights and freedoms wherever they reside with their dignity respected. Under the topic of self-fulfillment, older people should be able to pursue opportunities in numerous spheres to pursue their potential. Finally, under dignity, older people should live in dignity and security and *be free of exploitation and physical or mental abuse.* They have the right to be treated fairly and valued independently.

5.12 The Madrid International Plan of Action on Ageing (2002)

The monumental Madrid International Plan of Action on Ageing (MIPAA) and the Political Declaration, adopted at the Second World Assembly on Ageing (UN 2002), emphasized how the present and future world should address a 'society for all ages.' Its three priorities are older persons and development, advancing health and well-being into old age, and ensuring enabling and supportive environments. The MIPAA was intended to be:

> …a resource for policymaking, suggesting ways for Governments, non-governmental organizations, and other actors to reorient the ways in which their societies perceive, interact with and care for their older citizens.

The plan represents the first time governments agreed to link questions of ageing to other frameworks for social and economic development and human rights and links with previous United Nations conferences and summits.

Most pertinent to elder abuse is Priority Direction II, Advancing health and well-being into old age, and Priority Direction III, Ensuring enabling and supportive environments. Under Priority Direction II, the MIPAA stresses physical and mental health and ways to achieve it: health and well-being throughout an older person's life (Issue 1), Universal and equal access to health-care services (Issue 2), Older persons and HIV/AIDS (Issue 3), Training of care providers and health professionals (Issue 4), Mental health needs of older persons (Issue 5), and Older persons and disabilities (Issue 6). Under Priority Direction III, the MIPAA stresses enabling and enhancing social environments: Housing and the living environment (Issue 1), care and support for caregivers (Issue 2), Neglect, abuse, and violence (Issue 3); and images of ageing (Issue 4). Specific to Issue 3, the MIPAA stresses the elimination

of all forms of neglect, abuse, and violence of older persons (Objective 1). That older women are the especial victims of abuse is highlighted within the section as well as how often older women live in poverty and without legal protection, leaving them unable to participate in their own decision making and vulnerable to abuse. Actions to address the problem of elder abuse include education of professionals and the general public, especially through use of the media; the abolition of harmful widowhood rites; strengthening legislation to eliminate the problem; eliminating harmful traditional practices involving older adults; encouraging efforts of government and non-governmental organizations to address the problem; minimizing risks and vulnerabilities of older women; and encouraging research in order to understand the problem and its sequelae.

Objective 2, the creation of support services to address elder abuse, includes five action steps. The MIPAA recommends establishing services for victims of abuse, encouraging professionals to report abuse when it is suspected, encouraging professionals to inform older persons who are suffering from abuse about services available to them, including information on elder abuse in training of people in caring professions, and creating informational programmes educating the older people themselves about elder financial exploitation.

According to Zaidi (2018), despite both promise and progress, implementation is highly uneven due to resources, political will, and reliable data. Although one problem is lack of age-disaggregated data in many countries, Zaidi stresses that the primary problem is that the MIPAA monitoring toolkit was improperly developed. Thus, monitoring, when conducted, was not uniform and not well associated between efforts and policy development, implementation, and evaluation. Zaidi suggested the development of a dashboard of indicators harmonized with key priorities of the MIPAA.

5.13 Open-Ended Working Group on Ageing

The Open-Ended Working Group on Ageing was established by the General Assembly by Resolution 65/128 on 21 December 2010. The working group has focused on the existing framework of the human rights of older persons and the identification of gaps and solutions to address them. One possibility is for the work to lead further instruments or measure, such as a convention on the rights of older persons. Below are highlights from the American Bar Association (ABA) Commission on Law and Aging on activities related to the Open-Ended Working Group on Ageing in 2015.

5.14 ‘2015 Was a Big Year for International Progress’

In 2015, the Commission continued to participate in the annual meetings of the UN Open-Ended Working Group on Ageing in support of the new ABA Liaison Professor Bill Mock of John Marshall Law School. The Working Group continued to engage in extensive inquiry and debate about whether the UN should pursue a separate convention on the rights of older persons, or instead seek to strengthen the enforcement of existing international normative standards as they may apply to older persons. That question remains a threshold sticking point to consensus.

The European Union, the US, Canada, Australia, and Japan are opposed to drafting such a convention, while the vast majority of low and middle income countries are strongly in favor. High income industrialized countries claim that the existing legal instruments (such as the Convention on Economic, Social and Cultural Rights, for instance) apply to all people, including older persons, and are sufficient. Gaps arise because governments fail to implement the relevant conventions. Countries supporting a specialized convention, as well as nearly every non-governmental organization that has addressed the Working Group, claim that, since the existing instruments do not identify older persons as such, the instruments are too non-specific, fragmented, and vague in their application to older persons. As a result, this demographic group ‘falls between the policy cracks.’ Moreover, without the explicit international legal protection conferred by a convention, older persons remain vulnerable to poverty, abuse, neglect, illness, and premature mortality.

The ABA Commission and the Working Group have spoken in favor of initiating work on a convention. They have collaborated with the John Marshall Law School and Roosevelt University in distributing a model international convention, referred to as the Chicago Declaration. The model is an evolving work, based on continuing input from experts and stakeholders internationally, including the ABA Commission. The hope is that this declaration will concretize thinking about the organization and a future convention.

On the regional level, the movement toward an inter-American convention achieved a milestone. On June 15, 2015, the General Assembly of the Organization of American States (OAS) adopted the *Inter-American Convention on Protecting the Human Rights of Older Persons*. Outgoing Commissioner Marcos Acle and first-year Commissioner Ivan Chanis were both directly involved in the process in their professional roles at the OAS. The convention represents a major step forward in addressing the human rights needs of older persons. The instrument was immediately signed by governments of Argentina, Brazil, Chile, Costa Rica, and Uruguay at OAS headquarters in Washington, DC. For the convention to enter into force, at least two signatory countries must not only sign it but also they must ratify it.

The purpose of the convention—the first regional instrument of its kind in the world—is to promote, protect, and ensure the recognition and the full enjoyment and exercise, on an equal basis, of all human rights and fundamental freedoms of older persons in order to contribute to their full inclusion, integration and participation in society. The starting point of the convention is the recognition that all existing

human rights and fundamental freedoms apply to older people and that they should fully enjoy them on an equal basis with other segments of the population. The Convention will strengthen the legal obligations to respect, promote, and ensure the human rights of older persons. Its ratification will carry the obligation of States' parties to adopt measures to guarantee a differentiated and preferential treatment to older persons in all spheres.

Not surprisingly, the US has not been a supporter of the OAS convention or of the proposal for a UN convention. The US prides itself on its commitment and innovation in protecting the rights and quality of life of older Americans. Historically, the US has been reluctant to allow itself to be subject to any laws or rules created and enforced by non-U.S. authorities. Nevertheless, treaties or conventions widely adopted by other nations tend to affect legal thinking and analysis occurring in American law—and sometimes in profound ways (Bifocal 2018.)

As the ABA article mentions, the Chicago Declaration on the Rights of Older Persons provided a document that offered participants a vision of what a convention on the rights of older persons could be. The Chicago Declaration was introduced at a side event where it was shared as a working product of scholars, advocates, and policy makers from more than a dozen countries. The document was built upon the foundation of previous international human rights instruments and regional and international instruments promoting the rights of older persons. The Open-Ended Working Group continues its activities with the Tenth Working Session in April 2019.

5.15 Conclusion

Efforts to address the problem of elder abuse were slow to capture public attention. Advocacy in the late 1940s and early 1950s had its genesis in the atrocities of the recent world wars and a concerted effort, both in the US and internationally, to prevent them from happening again. The issue of elder abuse was first regarded as a private, family problem for which large-scale prevention and intervention efforts were deemed inappropriate. However, at the local level and on the scale of governments, the tide of opinion was turning such that over time the issue became one that emerged as a public sphere problem, one that affects all of society (a realization that is continuing to evolve to this day). When public awareness impelled the issue into the political and public sphere (through notable efforts of advocates and politicians alike), more and more influential sectors of action (e.g., healthcare, law, finance) became involved in efforts to prevent the problem from happening and to intervene more appropriately and with adequate resources when it did.

Another understanding critical to action was the realization that the problem affected people of all ages. When the problem became one for all generations, efforts related to its discovery and prevention began to take hold on a greater scale (the 1995 WHCoA was particularly notable as a U.S. example).

Internationally, the issue of human rights was emerging, and so was the dawning understanding that human rights should be extended to more and more groups of people around the world and that social and economic status had much to do with impeding the exercise of human rights for all. The international documents, the UNDHR, the UNPOP, and the MIPAA all expanded the human rights theme. The extension and focus of those rights were first on children and were later broadened to older adults. However, it was not until 1992 that a major international document on human rights included a section specifically addressing elder abuse. Although much is being done to connect the human rights of older persons around the world, much work remains to be done to crystallize aspirational laws and declarations and parlay them into (measurable) action and outcomes, as the work of the Open Ended Working Group on Aging attests.

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Chapter 6
'If You Do Not Believe That It Happens You Won't See It Either!'-Sexual Abuse in Later Life

Wenche Malmedal

6.1 Introduction

Sexual abuse is one of the categories of elder abuse and defined as 'nonconsenting sexual contact of any kind' (Teaster and Roberto 2004a). Attention was first drawn to this type of abuse during the 1990s (Ramsey-Klawsnik 1991; Holt 1993; Bennett and Kingston 2013). One of the first studies on sexual abuse in later life was conducted by Ramsey-Klawsnik (1991), and in 1999, a conference under the title "The Great Taboo" was organized by *Action on Elder Abuse*, a charitable organization in the United Kingdom. Because of the hidden nature of late life sexual abuse and the difficulties in obtaining data on the topic, a paucity of research exists from domestic as well as institutional settings and there is still a gap in knowledge around older victims of sexual abuse. Single reported acts from media and court systems demonstrate that age is no protection against sexual victimization, either in community dwelling older adults or for nursing home residents, but this problem has not gained much attention in research. However, recently several studies have addressed the issue (Burgess et al. 2008, Malmedal et al. 2015, Rosay and Mulford 2017, Alon et al. 2018). Professionals in health care and social welfare systems are in key positions to be able to identify and detect sexual abuse. Nevertheless, it is likely that they do not have the necessary knowledge about this taboo topic. This chapter will help professionals in identifying sexual elder abuse, as well as providing them with relevant knowledge about how to deal with such cases.

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6.2 Defining the Issue

An older adult can be exposed to sexual abuse from a stranger or acquaintance, a spouse/partner, a child, a grandchild or other relatives, a care provider, or a co-resident (in residential care facilities).

Sexual abuse defined as "nonconsenting sexual contact of any kind" is said to be the most hidden form of elder abuse (Teaster and Roberto 2004a, b) and is the least acknowledged and reported type of elder mistreatment. Sexual abuse takes several forms; some include physical contact, and others do not. Sexual abuse can include threat or coercion to participate in a sexual activity. This can range from being exposed to aggressive obscenities and behavior, being forced to watch porn to consummated rape. The definition of sexual abuse includes (but is not limited to) unwanted touching and all types of sexual assault or battery, such as rape, sodomy, coerced nudity, and sexually explicit photographing (National Centre on Elder Abuse n.d.). Sexual contact with any person incapable of giving consent is also considered sexual abuse.

In most of the literature on elder abuse, sexual abuse is a main category along with physical, psychological, financial abuse, and neglect. Some studies, however, categorize sexual abuse as a subcategory of physical abuse, which makes it even more difficult to estimate the prevalence. According to the World Health Organization, sexual well-being is a part of a person's global well-being (WHO 2006). Sexual activity is acknowledged as an important part of relationships in late life, and older persons with active sex lives are reported to have higher life satisfaction (Hodson and Skeen 1994). The problem faced by professionals is the question of the older person's consent when there are challenges in decision-making capacity, in addition to the concerns raised by relatives. Sexual activity among nursing home residents may be unproblematic for the residents themselves if both are able to consent, but the relatives may experience this as extremely problematic. Assessing sexual consent capacity is challenging and complex, but if sexual activity among cognitively impaired older persons is occurring, the capacity of both should be assessed and documented (Rosen et al. 2010). The professionals facing these issues need to balance the wish to support the sexual rights of the older person and the awareness that sexual activity may be non-consensual and thus regarded as sexual abuse.

6.3 How Often Does It Happen?

On global basis, there is no official prevalence statistics on the sexual abuse of older persons. A systematic review on elder abuse in community population identified a lack of consistency in definitions of elder abuse (Dong 2015) and some studies classify sexual abuse as a subcategory of abuse while others label it under physical

abuse. In addition, since the number and content of the questions used in the studies varies, as well as differences in how the calculation is done, comparing the different studies does not make much sense. Pillemer et al. (2016) conducted a scoping review on elder abuse and found that researchers generally developed their own set of questions to screen for elder sexual abuse. Studies consistently operationalized sexual abuse cases as one or more events occurring in a given time period.

Despite methodological and definitional challenges, the results from studies conducted prove the presence of elder sexual abuse. Most of the studies are conducted in community dwelling settings. Studies in residential care settings are rarer when comes to research in elder abuse, including sexual abuse. Pillemer et al. (2016) found in a scoping review that elder sexual abuse 1-year prevalence ranged from 0.04% to 0.8%, with a mean of 0.7%. Prevalence survey reports from United Kingdom and Ireland show that 0.3% had experienced one or more instances of sexual abuse since the age of 65 (O'Keeffe et al. 2007, Naughton et al. 2010) and a prevalence study conducted in the United States (US) shows that 0.6% of older persons are exposed to sexual abuse (Acierno et al. 2010). A study from a district in Sweden (Kristensen and Lindell 2013) reports that 2.2% of females and 1.2% of males had been exposed to sexual abuse after the age of 65 years. A national prevalence study on abuse among community dwelling older adults in Norway (Sandmoe et al. 2017) included sexual abuse in the questionnaire and found that 1.4% of the older adults had experienced this form of abuse after the age of 65 years while 0.5% had experienced this the last 12 months.

The review conducted by Pillemer et al. (2016:195) did not cover elder abuse prevalence in institutional settings because of the general lack of research in this environment, stating 'No reliable prevalence studies have been conducted of such mistreatment in nursing homes or other long-term care facilities.' However, a few studies have investigated sexual abuse in residential care facilities, such as nursing homes and the results indicate the incidence of sexual abuse of older people (Drennan et al. 2012; Yon et al. 2018). Rosen et al. (2010) state that even though no studies were found that had systematically examined the prevalence of sexual abuse in long-term care facilities, sexual aggression and sexual abuse occur, with fellow residents as the most common perpetrators. An extensive literature review conducted by Malmedal et al. (2015) shows similar findings, however, none of the studies included in the review referred to prevalence studies. Rather, the studies examined related to cases of abuse reported to Adult Protective Service or referrals to the court system, all from United States. The Irish nursing home study (Drennan et al. 2012) found a low rate of sexual abuse perpetration. Nine (0.7%) of the 1241 staff had observed a colleague talking to or touching a resident in a sexually inappropriate manner, while three (0.2%) of the respondents admitted that they themselves had spoken to or touched a resident in a sexually inappropriate manner. In Norway, a few pilot studies have revealed that the phenomenon is present in nursing homes, but the true extent is not yet known, due to the lack of larger prevalence studies (Iversen et al. 2015; Malmedal et al. 2016).

6.4 Risk Factors and Warning Signs

Age is not *per se* a risk factor, but even though older adults are mostly healthy and independent, age-related illnesses may increase the risk for sexual abuse. Cognitive impairments, like Alzheimer's disease and other types of dementia, are found to be risk factors for sexual abuse (Burgess et al. 2000a, b; Teaster and Roberto 2004a). Self-care limitations enhance the dependency and vulnerability of the older person and may increase the risk of being abused in any form including sexual abuse (Teaster and Roberto 2004a). Self-care limitations may be caused by physical or cognitive impairments. Research suggest that victims of elder sexual abuse are likely to be cognitively and/or physically impaired (Rosen et al. 2010) and dependency might set up the dynamic for potential abuse (Teitelman 2006). Sexual abuse in old age is directed primarily against women (Teaster and Roberto 2004a; Abramsky et al. 2011), regardless of setting. A factor contributing to sexual violence against women in domestic settings may be the coercive control exhibited by an abusive husband (Ramsey-Klawsnik 2004). This abuse may have been going on for many years and the domestic violence has simply "grown old". A literature review (Malmedal et al. 2015) found that both men and women are victims of nursing home sexual abuse, but in the majority of cases reported, women constituted the victims. The World Health Organization (WHO) (2002) states that official statistics vastly underrepresent male victims of sexual abuse, and this seems to be the case also for elder abuse. Furthermore, Malmedal et al. (2015) shows that most victims of sexual abuse in nursing homes were cognitively impaired (dementia, stroke, and brain injury), had a psychiatric diagnosis and/or were physically frail (wheelchair, bedridden, paralyzed, and reduced mobility), and had somatic illnesses. Regardless of gender, the older residents (age 79–99 years) were more at risk of sexual abuse. This could support the view that other factors apart from gender are more important in the oldest age group. This is also underlined in the WHO report (WHO 2002), where it is, based on community-based prevalence studies, concluded that older men are at risk of abuse by spouses, adult children, and other relatives in about the same proportion as women.

A particularly high-risk group is that of homeless or marginally housed older people. Little is known about sexual assault against older persons who are homeless. We do not know whether the risk for sexual abuse is higher among older homeless persons, than other older populations, but findings suggest that this phenomenon also occurs in this group, and that these older women are more likely to be sexually assaulted than men (Dietz and Wright 2005).

Signs and indicators of sexual abuse against older adults can be either behavioral or physical. They include the following:

- Bruises around the breasts or genital area or inner thigh
- Unexplained venereal disease or genital infections
- Unexplained vaginal or anal bleeding
- Irritation or pain of the anus or genitals
- Difficulty in walking, standing or sitting

- Marked changes in behaviour
- Torn, stained, or bloody underclothing
- An older person telling you they have been sexually assaulted or raped
- Panic attacks
- Signs of Post-Traumatic Stress Disorder (PTSD)
- Symptoms of agitation
- Social or emotional withdrawal from others
- Engaging in inappropriate, unusual or aggressive sexual activities
- Suicide attempts
- Engaging in unusual or inappropriate actions that appear to be from a sex role relationship between the perpetrator of elder sexual abuse and the victim. (Action on Elder Abuse (n.d.), Nursing Home Abuse Centre (n.d.))

It is important to be familiar with the different forensic markers, signs and symptoms that indicate elder sexual abuse. It is also important to be responsive to any verbal or nonverbal disclosure from the older person. It might not be that they are using direct language to disclose sexual abuse, but may 'beat around the bush', directly avoiding naming the abuse but trying to disclose. Shame and embarrassment is not cited in the list above, but victims of elder sexual abuse experience shame and embarrassment, as do younger victims, and this reduces the likelihood of disclosure of the abuse (Teitelman 2006).

6.5 Who Are the Offenders?

Within family settings, the offender may be an acquaintance or a friend, stranger, spouse or partner, other relative, or service provider (Baker et al. 2009). In the majority of the cases, it seems that current or former spouses or partners are the offender, but adult children, grandchildren and other relatives may also sexually abuse their older relatives (Ramsey-Klawsnik 2004; Roberto and Teaster 2005; Bonomi et al. 2007).

In institutions, residents are mainly sexually abused by co-residents or staff members (Ramsey-Klawsnik et al. 2007; Rosen et al. 2010; Iversen et al. 2015). Co-residents identified as offenders of elder sexual abuse are characterized by having some psychopathology such as psychiatric illnesses or dementia and/or alcohol/drug abuse. Some may have criminal histories, including sexual assault convictions (Teaster et al. 2007). Hypersexual behaviors, which are not uncommon in cognitively impaired persons, are a potential risk factor for sexual aggression towards co-residents. Hypersexual behavior may also occur due to medication for certain diseases, such as Parkinson (Rosen et al. 2010). Such behaviors include masturbating in the presence of others, touching others in inappropriate ways, and talking to others in a sexually inappropriate manner.

In a study on convicted perpetrators in 52 cases of sexual abuse against older persons (Jeary 2005), around one-third of the perpetrators were motivated primarily

by sexual gratification. The age range of the offenders was 16–70+ years. Perpetrators reported that they were sexually attracted by older persons, and liked to masturbate while watching 'granny porn'. The concept "gerontophilia" is not well researched, but is described as a specific sexual inclination towards older persons and may at times explain the sadistic attacks made upon them (Kaul and Duffy 1991). According to Burgess et al. (2000b) gerontophiliacs represent a group of assailants who often look for employment in nursing homes where they can have access to older people.

It is also important for professionals to acknowledge that even though there can be a gender aspect to the sexual abuse of older people where alleged and suspected offenders are mainly men, and the victims are mainly woman, one must be aware of the possibility for men to be abused by women and same sex abuse (Iversen et al. 2015).

6.6 Why Is It Still a Hidden Problem?

Societal ignorance and disbelief regarding elder sexual abuse may play an important role why cases are not detected and that the victims are not receiving appropriate and early intervention. Sexual abuse of older adults is still not recognized as a social problem in many countries, and along with the general lack of mandatory reporting systems, this problem is often hidden and not acknowledged among professionals or in society. Some countries and states do have mandatory reporting of elder abuse cases, but even where this exists, health care providers are not always aware of the mandatory reporting laws or how to enforce those (Hirst et al. 2016).

Health professionals and social workers play an important role in identifying elder abuse cases, including sexual abuse, and the lack of awareness of the abuse may leave the problem unsolved for the older person. Professionals working with older persons may not have enough knowledge to detect, investigate and initiate actions to help the older victim. It is easy for them to believe that what they observe may be a consequence of old age, rather than an abusive act. Studies with staff in Norwegian nursing homes revealed that they had very little knowledge of the phenomena, and that they were not aware of how to act if they identified cases of sexual abuse at their workplace (Iversen et al. 2015; Malmedal et al. 2016). A study among nursing home staff (Iversen et al. 2015) shows that sexual abuse of older residents is still a taboo topic. Acts of sexual abuse are difficult to imagine; it is hard to believe that it occurs. The fact that staff are not aware that it could happen, or have a hard time believing that it actually happens, can amplify the residents' vulnerable position as potential victims of abuse, and it makes it even more challenging to report or uncover such acts. Within families, it may be even harder to believe that a son is capable of raping his mother, or that someone close will take sexual advantage of a frail older person with physical or mental disabilities. The societal and professional disbelief may be rooted in ageism. Older persons are seen as non-sexual individuals and it is therefore hard to imagine that sexual abuse against older

residents happens (Iversen et al. 2015). A common stereotype perception is that sexuality and older people is a non-entity, in other words older people are not interested in sexuality. This view is supported by an extensive literature review showing that older people experience a tension between the desire to express their sexuality and social conventions that inhibit them from doing so (Gewirtz-Meydan et al. 2018). Connolly et al. (2012) suggest that by not having knowledge of sexuality related to older persons and of sexual abuse against older persons, we are undermining their health, safety, and well-being. There are also occasions when sexual abuse or assault is reported but is not taken seriously because of the victim's age or assumptions about their mental capabilities.

It is important that professionals understand the challenges in disclosing elder sexual abuse. The older person him/herself may be unable to report, due to lack of physical or mental capacity. They may also be dependent on the abuser for care and basic needs and fear punishment if they tell someone about the abuse. In addition, the feeling of shame and embarrassment that someone close to them would do such a thing will stop them from reporting. If the abuser is a child or grandchild, the older person may be reluctant to report; they do not want their "loved" ones to get into trouble (RAINN 2019). In addition, if the older person discloses the abuse, they might not be believed due to assumed or actual deteriorating mental capacity and old age. In residential care facility settings, the staff may be reluctant to report an abuse if this involves a co-worker. This co-worker may have a good reputation and the instinctual reaction might be disbelief, and a wish not to get involved (Teitelman 2006). From the administrator's point of view, a disclosure of sexual abuse occurring in their facility may be a threat to their reputation and along with a wish to avoid a possible lawsuit; this may stop reports from being passed on.

6.7 Responses to Sexual Abuse

Addressing elder sexual abuse requires a multi-dimensional approach. On an individual level, professionals have a clear responsibility to take action on any suspicion of sexual abuse. When sexual abuse is known to have happened, or is suspected to have happened, the focus must be on immediate intervention.

A pilot study among staff in Norwegian nursing homes showed that staff were not aware that sexual abuse might happen and the majority did not know how to handle such cases if they occurred (Malmedal et al. 2016). The nursing staff asked for more education on the topic, appropriate tools to assess possible abuse, and guidelines for interventions. What was apparent in this study was that professionals must face their own ageism regarding older persons and sexuality, since not viewing older persons as sexual individuals may hinder their sensitivity to detecting sexual abuse. Staff also need to be aware of the serious consequences of sexual abuse and the need to respond as early and comprehensively as possible. A study by Teaster and Roberto (2004a) shows that a strikingly low number of victims of sexual abuse in nursing homes received physical or psychological treatment for the abuse, while

a higher number of the perpetrators received psychiatric treatment. Yet both victims and offender require help. Staff should also have knowledge concerning techniques for the preservation of evidence of sexual abuse; wrongdoings at the early stage could jeopardize the prosecution process against a perpetrator. Staff are mandated by law and regulations to provide safe and high-quality care, and when this is not the case, as when sexual abuse occur, the staff need to report and take appropriate actions.

Responding to the sexual abuse of older people requires a multi-level response. On the organizational level, the nursing home and home care management have a duty to ensure that their staff are trained to handle elder sexual abuse cases, and that they know when, how and where to report. Findings from a literature review show that most nursing homes did not handle situations of sexual abuse in an adequate way (Malmedal et al. 2015). Many nursing homes did not take proper action in suspicions of sexual abuse or they delayed reporting it to authorities. There was also a lack of documentation of abuse. Consequently, recommendations from Burgess et al. (2000a) for facility responses to alleged sexual abuse are amongst others immediate medical attention for victims, documenting detailed information, and collaborating with law enforcement. Staff training is also imperative focusing on signs and symptoms of suspected sexual abuse, patterns of abuse, victim impact, perpetrator behaviors and appropriate responses (Burgess et al. 2000a).

However, recognition and detecting elder sexual abuse can be difficult. Health professionals, whether in community, acute care or the residential care setting need to be trained to implement screening tools for proper detection of elder sexual abuse. Furthermore, healthcare professionals must also be clear about their intervention responsibilities in line with safeguarding policy and legislation. A supportive working culture that encourages staff to speak up on behalf of the patients is important to facilitate the disclosure of elder sexual abuse, thus whistleblowing should be seen as a mechanism to improve care for older persons.

Resident to resident sexual aggression is an important issue. Teaster and Roberto (2004a) underscore the necessity of adequate staffing and appropriate placement of residents with behavioral problems. Vulnerable nursing home residents should be protected by the facility and safeguarded to make sure they are not abused by other residents.

On the societal level, elder abuse should be on the agenda for policy makers, and the severity of such acts must be highlighted through public awareness. Furthermore, there is a need for comprehensive policies and reporting systems as these represent an important step in seriously addressing sexual abuse against older persons (Malmedal et al. 2015). Some countries have independent advocacy services for older people and mandatory reporting systems for elder abuse cases. This should be implemented in all countries to ensure that fundamental safety for older persons are secured. Other strategies on this level must target ageism in society and change the negative stereotyping of older persons and upgrade the value of the work done by caregivers in care for older persons.

The WHO (2002:142) states that 'prevention starts with awareness' and emphasizes that health care providers should receive basic training on the detection of elder abuse. Recognition of the problem of sexual abuse in older adults can be promoted through education of the professionals and through public campaigns to raise awareness in the society. In applying multiple methods of both prevention and intervention, we can promote a safe environment of older people and ensure human flourishing in older age.

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Chapter 7
Self-Neglect in Older Adults

Mary Rose Day

7.1 Introduction

Medical advancements have significantly increased life expectancy, and people over the age of 65 (older adults) are the fastest-growing population in the world (World Health Organization 2015). Population aging has brought to the fore prevailing under-discussed public health issues such as self-neglect. The National Centre on Elder Abuse (NCEA) posits that Self-Neglect (SN) is '*the behaviour of an elderly person that threatens his/her own health and safety'* (Adminstration on Aging 2016). Self-neglect can vary in presentation and severity and was first identified in the 1950s. A variety of terms such as Diogenes syndrome (Reyes-Ortiz et al. 2014), and domestic squalor (Snowdon et al. 2012) have been used to describe and define self-neglect (Gibbons et al. 2006; Lauder et al. 2009). A concept anlysis by Day (2016) concluded that self-neglect can manifest both externally and internally and defining attributes were environmental neglect and cumulative behaviors (service refusal, isolation, poor social networks, reduced engagement, poor self-care, neglect of health, hygiene, nutrition, and finances) that could be intentional or non-intentional.

Self-neglect can have a significant impact on older adults, family members and communities (Day 2017a, b, Payne and Gainey 2005). Adverse outcomes associated with self-neglect include: caregiver neglect (Dong et al. 2013), emotional and financial abuse (Mardan et al. 2014) and significantly increased mortality that can be related to cancer or endocrine and nutritional deficiencies (Baruth and Lapid 2017; Dong et al. 2009; Reyes-Ortiz et al. 2014; Schafer et al. 2017). In addition, evidence supports that self-neglect results in increased use of hospital services (Dong and Simon 2013a, 2015; Schafer et al. 2017), emergency department visits

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(Dong et al. 2012a), hospice care (Dong and Simon 2013b) and nursing home placement (Lachs et al. 2002).

Safeguarding and protection of adults who self-neglect is one of the most challenging and frustrating issues that health and social care professionals encounter (Day et al. 2012; Braye et al. 2011). Determining adults' mental capacity to make an autonomous decision is a central aspect of self-neglect practice. Each self-neglect situation is unique and fluid and meaningful engagement, building relationships and trust with clients to improve behavior is important (Day et al. 2017; Day and McCarthy 2017). Derogatory terms have been appropriated to describe situations of self-neglect by younger people such as: 'scrubber', 'ragger', 'bag lady', 'slimy creep', 'tramp', 'lazinesss' and 'mental problems' (May-Chahal and Antrobus 2012:1483). The concept of self-neglect is complex and historically Bozinovski (2000) suggested the term 'self-neglect was a misnomer.

7.2 Conceptualization of Self-Neglect

Self-neglect was first identified in the 1950s and a variety of terms have been used and reviewed in health and social care literature to describe and define self-neglect (Cooney and Hamid 1995; Shah 1995; Snowdon et al. 2007). The terms used include senile breakdown syndrome (MacMillan and Shaw 1966), senile squalor syndrome (Clark et al. 1975), squalor syndrome (Shah 1995) gross self-neglect (Cybulska and Rucinski 1986), messy house syndrome (Barocka et al. 2004), senile recluse (Post 1982), domestic squalor (Snowdon et al. 2007, 2012) and Diogenes syndrome (DS) (Clark et al. 1975; Reyes-Ortiz et al. 2014). The term Diogenes syndrome often appears in the clinical literature in case reports as a diagnosis of self-neglect (Cipriani et al. 2012; Esposito et al. 2003; Ngeh 2000; Pavlou and Lachs 2006). Diogenes syndrome may be preceded by stressful events over the life course and is characterized by:

> …extreme self-neglect, domestic squalor, social withdrawal, apathy, a tendency to hoard rubbish (syllogomania), and a lack of shame of living condition. (Pavlou and Lach 2006:836).

Hoarding disorder is a new addition to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)–5th Edition (American Psychiatric Association 2013) and no reference or recognition is given to self-neglect or animal hoarding. Hoarding is characterized by persistent difficulty in parting with possessions, which results in the accumulation of belongings that congest and severely clutter and compromise home living space. Animal hoarding is often associated with self-neglect.

A collaboration between nurse researchers in Scotland and the United States defined self-neglect as:

> The inability (intentional or non-intentional) to maintain socially and culturally accepted standard of self-care with the potential for serious consequences to the health and wellbeing of the self-neglecters and perhaps even to their community. (Gibbons et al. 2006:16).

This definition captures the intentional and choice factors as well as the sociocultural influence of the behavior and potential of the negative impact of self-neglect for the individual, his or her family, and the community.

The Elder Justice Act (EJA 2010) in the United States defined self-neglect as:

> An adult's inability due to physical or mental impairment, or diminished capacity, to perform essential self-care tasks including (A) obtaining essential food, clothing, shelter, and medical care; (B) obtaining goods and services necessary to maintain physical health, mental health … (C) managing one's own financial affairs. (p. 785)

This definition offers a comprehensive and concise conceptualization of self-neglect. White (2014) suggests that adopting this definition would provide standardization for research. Operational definitions, categorization and conceptualization of self-neglect differ nationally and internationally (Braye et al. 2011; Daly and Jogerst 2003). Neglect and self-neglect are frequently categorized and grouped with elder abuse (National Centre Elder Abuse 2016). Self-neglect has been sidelined in the context of abuse and neglect and designated as *'the orphan'* by O'Brien (2014).

There is no one theory or explanatory model that can explain self-neglect (Paveza et al. 2008). Self-care theory explains only some features of self-neglect (Lauder 2001, Pavlou and Lachs 2006). Gibbons (2009) determined that self-neglect theory consists of two main concepts: self-care agency and deliberate action.

A number of conceptual models and frameworks have been used to describe and understand self-neglect (Day and McCarthy 2016, Dyer et al. 2007a, b, Iris et al. 2010, Paveza et al. 2008). Dyer et al.'s (2007a, b) etiological model of elder self-neglect, based on over 500 cases, described it as multiple deficits in physical, social, and medical domains as risk factors for elder self-neglect. Paveza et al.'s (2008) risk vulnerability model focuses on internal and external risk factors as a framework for the study of self-neglect and defines elements of risk and vulnerability. Iris et al.'s (2010) conceptual elder self-neglect model captures the complex interplay between physical/psychosocial and environmental influences and the wide range of individual and population-level determinants and predisposing influences. In summary, there is no one all-encompassing explanatory model of elder self-neglect.

7.3 Epidemiology, Incidence and Prevalence of Self-Neglect

Self-neglect among older adults is the most commonly reported allegation to Adult Protective Services (Dyer and Reyes-Ortiz 2017). There is a growing body of research evidence on self-neglect, but a dearth of information remains on how to systematically estimate the prevalence and measurement of self-neglect (Abrams et al. 2018; Day and McCarthy 2016; Dong 2017). According to the National Centre of Elder Abuse (1998) incidence study in the United States, for every one case of self-neglect reported to authorities, about five more cases go unreported, a phenomenon they refer to as the 'iceberg effect'. To date, there is no data on incidence or prevalence of self-neglect in adults presenting to acute hospital services (O'Connor 2017).

Early estimates reported the incidence of Diogenes syndrome as 0.5 per 1000 of the population in community dwelling adults aged 60 or over living at home (Berlyne et al. 1975). Australia cited an incidence of 0.7 per 1000 of people age 65 years and older and living in moderate/severe squalor (Snowdon and Halliday 2009). A seminal Irish survey (Hurley et al. 1997) concluded a prevalence rate of 3.8 per 10,000 for self-neglect in community dwelling adults. In Scotland, data from General Practitioner (GP) caseloads suggests that self-neglect prevalence rates vary from 166 to 211 per 100,000 people (Lauder and Roxburgh 2012). Day et al.'s (2016) retrospective review of student public health nurses' (PHNs) community profile and health need assessments (CPHNA) in Ireland suggested a prevalence rate for self-neglect of 142 cases per 100,000 population. Self-neglect was seen in all ages but prevalence was lower at 31 cases per 100, 000 in younger people. Irish prevalence data is, therefore, similar to data from GP caseloads in Scotland.

Data on self-neglect has relied on case reports from social service agencies and a number of population based studies that have shown a range of prevalence estimates. Dong et al. (2012b) assessed Personal and Environmental circumstance using a 21 item observations tool (5 domains: hoarding, poor basic personal hygiene, house in need of repair, unsanitary conditions and inadequate utilities). Prevalence of self-neglect for men aged 65–74 years was 9.5%; aged 75–84 years was 9.2% and for those age 85 or older it was 10.1%. The prevalence of personal and environmental hazards among women were 8.5% in the 65 to74 age group, 7.9% in 75–84 age group and 7.5% in 85 years and over age group. The prevalence of overall self-neglect increased significantly as health status lowered especially in men (Dong et al. 2012b).

The prevalence of self-neglect can vary greatly across ethnic groupings in populations. A study on 5519 older adults from the Chicago Health and Aging Project (CHAP) found a significantly higher prevalence of self-neglect among African–Americans (21.7%) and 5.3% among whites (Dong et al. 2012b, c). A cohort study by Dong and Simon (2016) of 3159 community-dwelling Chinese older adults in Chicago found that the overall prevalence of self-neglect was 29.11%, with 18.24% being classified as mild and 10.87% as moderate to severe.

In South Korea, Lee and Kim's (2014) study of 1023 older adults living alone reported that 22.8% of older adults had some form of self-neglect. In the Republic of Ireland (ROI), National Data on Safeguarding reported that 418 of concerns received, 7% of the overall cases, related solely to alleged self-neglect, and most related to people aged over 65 years (Health Service Executive 2016). The identification of self-neglect can be highly subjective and reports support that self-neglect is largely hidden and not reported. Self-neglect is a complex multifaceted entity, and is linked to a range of etiologies (Burnett et al. 2014).

7.4 Risk Factors for Self-Neglect

A dearth of rigorous longitudinal studies have impacted on the clarification of previous cross sectional data of associated risk factors that may lead to self-neglect (Dong 2017). Self-neglect was associated with a range of diseases include dementia, depression, cardio-vascular disease, diabetes, and other psychiatric disorders (Dyer et al. 2007a, b). Depression and cognitive impairment are major predictors of self-neglect in community-dwelling adults (Abrams et al. 2002). A decline in executive functioning was associated with greater risk of reported and confirmed elder self-neglect (Dong et al. 2010a). Reduced physical function, depression, executive dysfunction, and drug and alcohol abuse are associated with self-neglect (Dong et al. 2010b, c; Dyer et al. 2007a, b; Gibbons 2009; Pickens et al. 2013). Alcohol abuse, low self-rated health, and pain were associated with higher depression in people who self-neglect (Hansen et al. 2016). Self-neglect is significantly associated with increased risk of self-reported suicidal ideation in a United States Chinese population (Dong et al. 2017) and higher self-neglect scores were associated with significantly poorer quality of life in rural China (Zhao et al. 2017).

Self-neglect can affect adults across demographic strata and social classes (Hurley et al. 1997; Day et al. 2016). The factors associated with self-neglect include age, reduced social engagement and poor social support, (Dong et al. 2010c; Dyer et al. 2007a, b; Ernst and Smith 2011), pre-frailty (Lee et al. 2016), poverty and isolation (Spensley 2008), lack of access to health services (Choi et al. 2009), poor coping (Gibbons 2009), medical neglect (Burnett et al. 2014), non-compliance with medication (Turner et al. 2012), risk for harm (Tierney et al. 2004), and homelessness (Snowdon 2011).

Etiologically, self-neglect in later life has been linked to traumatic personal experiences (Band-Winterstein 2016; Band-Winterstein et al. 2012; Lien et al. 2016; Day et al. 2013). Unique insights into life history and narratives of people who self-neglect portrayed characteristics of suffering, loss, childhood abuse, uprootedness and migration (Band-Winterstein 2016; Day et al. 2013) and traumatic life events in early years (Lien et al. 2016; Monfort et al. 2017). Life history can influence intention to self-neglect and understanding current behavior in context of antecedents and life experiences of individuals who are self-neglecting as well as contextual and environmental effects is important (Band-Winterstein 2016). An investigation of farm animal welfare incidents observed serious health issues among farmers such as alcohol addiction, depression, loss following death of a parent, and stress due to increased paperwork (Kelly et al. 2011). High stress levels, economic vulnerability, depression, mental health problems and suicide (Devitt et al. 2015) among farmers may increase the risk for human self-neglect and impact on relationships between

farmers and their animals (Devitt and Hanlon 2018). Self-neglect is not just a lifestyle choice, antecedents and risks factors need to be explored and understood especially the past history of an adult who is self-neglecting reviewing their wishes and feelings in relation to the risks. Typically, self-neglect cases focus on severe cases, and threshold of what constitutes extreme self-neglect is subjective and views may differ between professionals (Day et al. 2013).

7.5 Assessment and Measurement of Self-Neglect

The absence of a specific self-neglect measurement instrument has impacted on both research and practice. A range of assessment tools have been developed to characterize and assess self-neglect objectively and include the Self-Neglect Severity Scale (SSS), 26 items (Dyer et al. 2006), Self-Neglect Assessment Measure (Day and McCarthy 2016), Abrams Geriatric Self-Neglect Scale (AGSS) (Abrams et al. 2018) and the Elder Self-Neglect Assessment (ESNA) (Iris et al. 2014). A 10 item Environmental Cleanliness and Clutter Scale (ECCS) measures and observes the severity of domestic squalor and hoarding (Halliday and Snowdon 2009).

The Self-Neglect Severity Scale (Dyer et al. 2006) includes observational and self-report data and 3 domains of self-neglect as indicators: Personal hygiene (example: dirty hair, clothing, unkempt nails and skin), impaired function (example: decline in activities of daily living and cognition); and environmental neglect (example: unclean house or yard and inability to manage material goods accumulated over the years).

The Self-Neglect Assessment Measurement (SN-37) (Day and McCarthy 2016) includes 37 items and 5 factors: environment (12 items), social networks (7 items), emotional and behavioral liability (8 items), health avoidance (6 items) and self-determinism (4 items). Each item is completed based on three-point scale ranging from no evidence, yes, and don't know. Principal components factor analysis supported the SN-37 SN-(factor loadings = 0.4 or >), explaining 55.6% of the variance and cronbach's alpha (α) for four subscales ranged from 0.83 to 0.89 and one subscale was 0.69. The SN-37 can be used not only to measure SN, but also to develop interventions in practice.

The Geriatric Self-Neglect Scale (Abrams et al. 2018) has three subscales Subject, Observer, and the Overall Impression and six domains (prescription medicines, personal care, nutrition, environment/housing, financial stewardship and socialization). Environmental neglect is a central factor and foci in the measurement of self-neglect (Day and McCarthy 2016; Abrams et al. 2018). At present no objective measure is used in the assessment of self-neglect in the Republic of Ireland. The domains for assessment of self-neglect in the Health Service Executive policy (2014) are personal appearance, functional assessment and medical needs, environment and nutrition. There is considerable variation in the continuum and severity of self-neglect (range of behaviors and environmental conditions) and threshold to which the word extreme self-neglect and squalor may be applied.

7.6 Legislation and Policy

There are variations in State laws, policies and services internationally on elder abuse and self-neglect. State laws and processes differ across the United States; some states embrace self-neglect under adult protective services and many include self-neglect under definition of elder abuse (Teaster et al. 2006). Since 2014, England has widened the remit of legislation and policy to include self-neglect (Department of Health (DH) 2017), Care and Support Statutory Guidance (DH 2017). Scotland includes self-neglect within the code of practice (Scottish Executive 2014) that supports the implementation of the Adult Support and Protection (Scotland) Act (2007). This differs in Australia where self-neglect and squalor are not categorized as elder abuse as there is no third party involvement (McDermott et al. 2009). In Australia, community professionals (health services, housing and council staff) differentiated between environmental neglect (squalor) and behaviours that involve neglect of self-care and hoarding (McDermott 2008).

The Safeguarding Vulnerable Adults policy in Ireland (Health Service Executive (HSE) 2014) defines a vulnerable person as an adult who may be restricted in capacity to guard himself/herself against harm or exploitation or to report such harm or exploitation (HSE 2014). Self-neglect is, therefore, excluded from the definition of elder abuse in Ireland. The HSE (2014) policy includes processes whereby concerns of extreme self-neglect can be referred to Safeguarding and Protection Teams. A number of definitions for self-neglect are included in the safeguarding policy (HSE 2014:45) such as: Self-neglect in vulnerable adults is a spectrum of behaviors defined as the failure to, (a) engage in self-care acts that adequately regulate independent living or, (b) to take actions to prevent conditions or situations that adversely affect the health and safety of oneself or others. The threshold for extreme self-neglect is highly subjective (Day and McCarthy 2016; HSE 2014). Moreover, Ireland lacks a legislative framework for safeguarding concerns (Donnelly et al. 2017) and current processes have been described as "ad hoc and reactionary" (Donnelly and O'Brien 2018: 3).

7.7 Assessment

In the context of safeguarding, decision-making capacity is a central factor and can affect an individual's perceptions of risk and need for intervention. Executive function is maintained by the frontal lobe of the brain and is necessary for planning, initiation, organization, self-awareness and execution of tasks which are critically important for protection and safety and independent living. Executive dysfunction inhibits appropriate decision making, problem solving and execution of decisions to enable adults to live safely at home (Schillerstrom et al. 2009, Terracina et al. 2015).

Self-neglect and hoarding cases are challenging and complex public health issues and place a significant burden on services and agencies resources. Hoarding disorder

and self-neglect are often hidden behind closed doors due to embarrassment, fear of eviction and limited insight or appreciation of their impact on health, well-being or environment and this will mitigate against people seeking help. A fall is often the precursor to a referral by a neighbor or family member to primary healthcare staff, community nursing, social worker or safeguarding team.

A risk assessment will need to be undertaken which gives consideration firstly to observation of the person in their home living environment. A comprehensive person–centred approach to clinical assessment needs to be undertaken that encompasses physical, psycho-social, behavioral and environmental factors once a concern or suspicion of self-neglect is identified. The assessment needs to identify unique needs of the older person, including their life history and story to understand underlying causes, meaning and reasoning of the behaviors and draw on knowledge from a wide range of sources and include family if available. Family can provide important information and context and can be a helping resource in developing care plans. However, they do not have decision-making authority (in Ireland at least) if the person has capacity or if there is no legal sanction for decision making (Enduring Power of Attorney, Wardship (until 2015 Act is implemented). The assessments will be able to determine and evaluate the need for assistance, prioritize immediate needs and safety issues, define potential or actual risk and concerns, assess available resource, and consequences of self-neglecting behaviors on health, safety and well-being. The risk assessment needs to identify potential fire hazards, pest infestation, and impact of hoarding on individual, family members and community. Risk has two variables: likelihood that something will happen and seriousness (outcome). Professional judgment applies sound professional knowledge and understanding to each decisions made.

A person-centred approach to care respects and promotes individual freedom of choice, dignity, independence and desire for personal autonomy and self-determination despite increasing dependency (Beauchamp and Childress 2012). The Assisted Decision Making Capacity Act (2015) takes a functional approach to capacity; there is a presumption that the person has capacity unless proven otherwise. The focus is on supporting people to make decisions and respecting individual's choice and recognizing the right to make unwise decisions. Capacity is decision specific, issue specific and time specific and should not be viewed as an attribute for all decisions made by the individual (Braye et al. 2017a). (see Phelan and Rickard Clarke, Chap. 3, in this volume).

Self-neglect is a complex area of practice and practitioners can feel isolated and helpless when balancing of autonomy, protection and risk (Mulcahy et al. 2017, Braye et al. 2017a). The most challenging elements of self-neglect practice was identified as 'fine balance' and related to the clients' capacity and/or refusal/reluctance to engage with services (Braye et al. 2014, Mulcahy et al. 2017). An ethical decision-making tool can be used to provide a stepwise approach to reflect on the ethical dimensions (values, rules and principles) and evaluate the merits and demerits of possible courses of action (Campbell and McCarthy 2017; Day and McCarthy 2017).

Through a conversational approach, engaging with client, building trust and a therapeutic relationship, health and social care professionals can foster relationships

with the older person. This encompasses negotiating and working with self-neglecting adults, assisting and helping them to think through their situation and concerns and identifying what is working well or not working. Forming an overall goal with the person is central to person centred care principles. Seeking family members' perceptions or insight into situation is important but they do not have decision-making authority. Accordingly, a health or social care practitioner makes a professional judgement based on the evidence and analysis and uses both subjective and objective knowledge. Care plans also need to ensure that interventions are proportionate to the significance and urgency of the situation and the behaviours.

In the event that the person is refusing services choosing to walk away, and 'non-interference' can have adverse outcomes in protection of person from harm. Maintaining contact, building a relationship of trust over time can lead to opportunities for the person to accept interventions and supports. Social support is critical to enabling and supporting people to remain in the community. In as far as possible, the assessment process needs to be person-centred and the person should be fundamental in co-developing a Safeguarding Plan to reduce or eliminate the identified risks (Day et al. 2015; Day and McCarthy 2017). Assessment is a process and ongoing review and evaluation of case is important. The HSE (2014) policy on self-neglect supports a multi-disciplinary and/or multi-agency involvement that supports shared risk management and shared decision-making. Practitioners need to be knowledgeable of the legislation and policy that can be relevant when responding to self-neglect in their jurisdiction. Effective self-neglect practice is founded on legal knowledge, ethical knowledge, emotional literacy, relationship-centered care, knowledge collated from a wide range of sources, organizational knowledge and decision-making (Braye et al. 2017b; Day and McCarthy 2017). Responding and intervening to improve clinical outcomes for people who self-neglect is very important (Lee et al. 2018).

7.8 Conclusion

Self-neglect is a growing serious and complex public health issue and excellent safeguarding practice must be at the core of adult protection services. There is no one overarching theory of self-neglect and absence of a universal definition and subjectivity in assessment has been problematic for research and practice. Mental health issues are associated with and a significant risk for self-neglect. Self-neglect is a complex and multifaceted issue and each case is unique and requires individualized person-centred responses and interventions. Knowledge, legal literacy and skilled application of legislation and policy are essential. Relationship based practice making safeguarding personal and understanding the person's life history, seeking positive engagement and flexible supportive responses can improve outcomes. Sometimes people who self-neglect may choose to live in situations that are considered as sustaining harmful environments which negatively impact their well-being. Professional judgment and ethical, person centred decision-making is central to

safeguarding process, while multi-disciplinary and multi-agency responses are central as are supervision and support. Consequently, reflective therapeutic engagement is essential to safeguarding adults who self-neglect and safeguarding is 'everybody's business'.

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Chapter 8
Financial Abuse of Older People

Amanda Phelan

8.1 Introduction

Elder abuse is an issue which permeates all societies. As global populations increase, safeguarding older people is a fundamental goal of societies. Within the manifestations of elder abuse, financial abuse (FA) has been shown to be the first or second more prevalent form of abuse (Naughton et al. 2010; Acierno et al. 2010; Yon et al. 2017). Yet, it is generally under reported, under prosecuted and under researched (Jackson and Hafemeister 2011). Consequently, in a White House conference on ageing in the United States, Pillemer et al. (2015) identified FA as a key policy and research area for action and it has been recognized as an important public health challenge (Payne and Strasser 2012; Yon et al. 2017).

This chapter examines the issue of FA of older people. Older people represent a disproportionate number of people who are financially abused as they may have accrued assets during their life and have 'nest eggs'. Financial abuse is the only form of abuse that can occur remote from the older person. Challenges in identifying FA can include a complex case presentation where there can be blurred lines regarding expenditure, capacity and consent as well as issues related to family expectations and cultural norms (Jackson and Hafemeister 2011). It is estimated that $2.9 billion was taken from older people in the United States in 2010 (MetLife Mature Market Institute et al. 2011) while in 2007/2008, it is estimated that approximately Aus$ 1.8–5.8 billion was taken from older Australians (Jackson 2009).

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8.2 Defining Financial Abuse

Globally, there are many different definitions of FA of older people (Fealy et al. 2012) and the diversity, changing modes of perpetration and case complexity can make universal understandings challenging (Centre on Policy on Ageing 2010). In addition, poor reporting, financial mismanagement, issues related to consensual intergenerational financial support, culture as well as blurred lines on costs in nursing homes exacerbate a lack of precision in common definitions (Crosby et al. 2008; Carter-Anand et al. 2014; Phelan and McCarthy 2016; Lloyd-Sherlock et al. 2018). Despite the lack of a common consensus in definition, Vancity (2014) suggest three general ways FA can be perpetrated; it can involve monetary abuse, legal abuse or property abuse perpetrated on an older person. This can also encompass a failure to access benefits and can involve mismanagement of funds or opportunistic abuse of finances by another person (Crosby et al. 2008). The World Health Organization (WHO 2002a: 128) identifies financial elder abuse as 'the illegal or improper exploitation or use of funds or other resources of the older person.' However, this definition is considered very wide-ranging and not specific enough to provide a comprehensive understanding (Darzins et al. 2009). In the Republic of Ireland and Northern Ireland, the definition of FA is more detailed and there are commonalities in terms of what constitutes this type of abuse:

> Actual or attempted theft, fraud or burglary. It is the misappropriation or misuse of money, property, benefits, material goods or other asset transactions which the person did not or could not consent to, or which were invalidated by intimidation, coercion or deception. This may include exploitation, embezzlement, withholding pension or benefits or pressure exerted around wills, property or inheritance. (DHSSPS and DoJ 2015: 13)

> Financial or material abuse includes theft, fraud, exploitation, pressure in connection with wills, property, inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits. (Health Service Executive 2014: 9)

Definitions are also blurred by issues of perceived consent of the older person in giving money or assets to another person, yet this could be because of undue influence or involve some form of deceit. Moreover, there can be multiple forms of FA being perpetrated on the older person, for example, theft, fraud, or pressure to sign wills (Jackson and Hafemeister 2011; Phelan et al. 2014). Dessin (2000) proposes four manifestations of FA. Firstly, it can constitute a criminal act, such as theft or robbery and is identified in the 2010 Elder Justice Act in the United States as an act of violence (Price et al. 2011). Secondly, it can be perpetrated through fraud and scams. Thirdly, Dessin (2000) suggests a special category for the nature of the relationship with the older person where the trusted person intentionally misuses the assets of the older person. The final category encompasses the negligent handling of the older person's assets, which may not be intentional.

Payne and Strasser (2012) examined FA in nursing homes, and suggest cases of embezzlement and fraud can constitute occupational crimes (for example, perpetrators who are staff in nursing homes). Although FA may often not meet standards of criminal

law (Smith 1999), Payne and Strasser (2012) advocate that legal responses need to be within the criminal justice system, rather than within the domain of civil justice.

In defining FA of older people, the issue of 'who' is the perpetrator is also relevant. For example, in the WHO (2002b) definition of elder abuse, it is stated that abuse occurs within a relationship of trust, clearly defining abuse by the type of perpetrator rather than the act of abuse. Bonnie and Wallace (2003), for example, state that FA by strangers is not a form of elder abuse while Jackson (2015) and Burnes et al. (2017) take a wider interpretation, suggesting personal abuse is constituted by people known to the older person, while commercial abuse represents opportunistic financial exploitation (i.e. scams and mass marketing fraud) (MMF) (Jackson 2015). A further consideration in defining FA is whether it is pure or hybrid. Jackson and Hafemeister (2011) propose that pure FA is where financial exploitation is the only maltreatment experienced by the older person, while hybrid abuse involves a clustering with physical abuse and/or neglect. The co-existence of abuse typologies in elder maltreatment is not uncommon (Naughton et al. 2010).

8.3 Prevalence

As there are varied definitions of FA, it is difficult to identify a true prevalence. This is compounded by indistinct boundaries related to culture and undue influence as well as the variety of methodological approaches used to study the topic. In addition, different studies have used varying age limits with some using 60 years or older while others use 65 years and older. Despite this, general prevalence studies of elder abuse have often identified financial abuse as either the highest or second highest form of abuse experienced by older people. However, these figures are likely to be underestimates of the true prevalence (Deane 2018).

Studies that have recorded the incidence and prevalence of FA in older people indicate that it predominantly occurs in the home environment (Centre for Policy on Ageing 2010; Wainer et al. 2010). Within this setting, the general prevalence of FA is unclear (Van Bavel et al. 2010) and commentators vary from a general reporting ratio for older people of 1:5 (Hannigan et al. 1998) to 1:25 (Wasik 2000) to 1:100 (Malks et al. 2003). The Social Care Institute for Excellence (SCIE 2011a, b) observe that older people who come to the attention of safeguarding professionals in health and social care, may not always report FA as a financial crime to police services. In addition, SCIE (2011a, b) notes that those with a high degree of independence may not be located within safeguarding services but may instead be in contact with other organizations and may also not be referred to the police service.

An incidence study in the US (NCEA et al. 1998) found that a significant number of confirmed elder abuse cases (30.2%) involved FA. However, prevalence rates can vary widely, even within countries as demonstrated in Table 8.1.

A wide prevalence variation was observed in a New York study (Lifespan of Greater Rochester Inc. et al. 2011) where the older person's self-reports of FA were compared with those reported by formal response agencies. In this study, a FA ratio

Table 8.1 Prevalence of FA in selected published studies

Country	Prevalence figure (12 month period) % (unless otherwise stated) Community based sample (unless otherwise stated)	Author and year
Finland	8.5	Kivela et al. (1992)
United Kingdom	0.7	O'Keeffe et al. (2007)
Ireland	1.3	Naughton et al. (2010)
United States	3.5	Laumann et al. (2008)
United States	5.2 Lifetime experience of FA by strangers was reported as 6.5%	Acierno et al. (2009)
Israel	6.4	Lowenstein et al. (2009)
World Health Organisation European Union	3.8	Soares et al. (2010)
Sweden	1.8	Soares et al. (2010)
Italy	2.7	Soares et al. (2010)
Lituania	2.8	Soares et al. (2010)
Austria	4.7	Soares et al. (2010)
South Carolina	6.6	Amstader et al. (2011)
South Africa	30	Bigala and Ayiga (2014)
Macedonia	12	Peshevska et al. (2014)
Norway	0.5	Sandmoe et al. (2017)
Global estimate (based on 52 studies in 24 countries)	6.8	Yon et al. (2017)
Canada	2.5	McDonald (2018)

of only 0.96 per 1000 was detected by such formal services as opposed to 42.1 per 1000 as reported by the older respondents. This suggests a major under-reporting of FA to official agencies, such as legal, police, health and social care services, which may be due to issues of embarrassment, family ties, not recognizing FA as an abuse perpetration as well as a lack of services being able to detect the abuse. Another study demonstrated a higher prevalence of FA being identified by proxy accounts as opposed to older people themselves (13% as opposed to 11%) which may prove important in terms of improving reporting sources (Acierno et al. 2009).

8.4 Prevalence in Care Settings

There are scant studies which looked at FA of older adults' formal care environments. One study demonstrates an 8.9% prevalence of financial abuse in hospital based older people (Cohen et al. 2007). Nursing home staff may perpetrate multiple incidences of FA over a period of time and on multiple residents (Payne and Strasser 2012). This may be facilitated by the relatively easy access to older people who have

cognitive and/or functional health challenges and the high degree of one to one interaction. For example, an early study by Harris and Benson (1998) suggests that one fifth of older people in nursing homes may be subject to FA on an annual basis. This compares to an Irish study of interactions and conflict in nursing homes (Drennan et al. 2012) where staff respondents, comprised of nurses or healthcare assistants, reported observing a colleague perpetrating FA once (0.9%) and between 2 and 10 times (0.3%) in the previous 12 months. Drennan et al.'s (2012) study also demonstrated low figures in the respondents' own self-reported perpetration of FA (0.3% for one episode of FA and 0.3% for between 2 and 12 perpetrations of FA) in the previous 12 months. A much higher figure of the prevalence of financial abuse in residential care was suggested by Yon et al. (2018), who examined data from three studies from three different countries. Yon et al. (2018) estimated a financial abuse pooled prevalence of 13.8% in nursing homes. Prevalence of FA in residential care for older people requires additional research, particularly in relation to issues related to residential care management of the person's money and also, how finances and property are administered by relatives when an person is in residential care.

8.5 Theories of Financial Abuse

Kemp and Mosqueda (2005) reviewed relevant literature and developed an eight item assessment for FA. These items, together with two FA conceptual frameworks in the literature (Wilber and Reynolds 1996; Rabiner et al. 2005) broadly identify three issues in the context of FA – (a) the vulnerability of the older person, (b) the quality of the older person-perpetrator relationship and (c) how this relationship is rendered exploitative. These three areas are discussed in detail below.

8.5.1 Vulnerability of the Older Person: Gender and FA

Some prevalence studies have identified that women are more vulnerable to financial abuse (NCEA et al. 1998; MetLife Mature Market Institute et al. 2011; Darzins et al. 2009). This may be influenced by the fact that women live longer and are proportionately larger in numbers in the general population of older people. Genderized roles may impact on the experience of FA. For example, due to traditional roles within marriage, older women may be inexperienced in managing finances, particularly after a spousal death, and may depend on others to assist with financial management which increases risk (British Columbia Healthlink BC 2014). Women are also considered to be more trusting and may believe their traditional genderised role as mother or caregiver translates to children or others having the entitlement to assets or finances. Conversely, older men may seek a replacement for a caregiving role and be vulnerable prey to female perpetrators. In particular, the 'Sweetheart Scam', can target lonely older men, although this form of FA may also

be perpetrated on older females (MetLife Mature Market Institute et al. 2011). Both sexes are considered to be particularly vulnerable to scams involving befriending, as social networks may decrease due to family having other commitments, geographic distance, immobility, cognitive function and the death of family members and friends, thus the older person's social capital (Rabiner et al. 2005) is diminished.

8.5.2 Ageing and FA

Financial abuse may occur at any age but common age related factors can heighten risk (Smith 1999; Burnes et al. 2017). For example, research has pointed to deterioration in the anterior insula in the brain which controls perception (Castle et al. 2012). The increased vulnerability to fraud is attributed to a reduced 'gut' response to cues of untrustworthy characters. Thus, the ageing brain contributes to impoverished acuity and enhances vulnerability to FA.

Age is a risk factor for functional and cognitive decline (Millān-Calenti et al. 2011; Prince et al. 2013) and such impairments have been linked to a risk of older people experiencing FA (Samsi et al. 2014; Choi et al. 1999; Wainer et al. 2010; Wood and Litchenberg 2017). Older people who experience cognitive or functional challenges may rely on others, particularly family members, for financial management assistance and such dependency can promote an unequal power dynamic within relationships, potentializing vulnerability. When health status declines, access to banking or engaging in daily activities involving money, such as collecting pensions, shopping, paying bills, could be rendered difficult and a third party, usually a relative, may be given access to the older person's finances. However, within such informal arrangements, there can be a lack of independent scrutiny regarding financial management. In relation to permitting a nominated individual to manage financial affairs, Setterlund et al. (2007) advocates using the routine activities theory to examine how the role of 'asset managers' is practiced (someone who has control over decisions and management of the older person's assets). This role may be undertaken in a responsible way, where asset managers keep judicious records and demonstrate transparency and accountability in being a 'capable guardian'. However, poor asset managers may engage in risky practices by blurring expenditure rationales, merging bank accounts and being accountable only to themselves (Setterlund et al. 2007). A careful review and monitoring of such activities can help to regulate and monitor for unacceptable financial activities, particularly within families.

As managing finances can be a complex task involving higher order executive function, older people with cognitive impairments may have a reduced ability to both protect themselves and whistle blow in the event of FA (Davies et al. 2011; Samsi et al. 2014). Financial capacity encompasses a range of skills from the basic counting of money to more complex activities such as bill paying and managing accounts. Marson et al. (2000) argues that an appraisal of financial capacity is often overlooked in health assessment, although this is a major element of individual autonomy and is fundamental to many legal and ethical issues pertaining to the

older person with cognitive decline. Yet, financial capacity encompasses many domains which Martin et al. (2008) identifies as (a) basic monetary skills, financial conceptual knowledge, (c) cash transactions, (d) chequebook management (e) bank statement management (f) financial judgment, (g) bill payment (h) knowledge of personal assets/estate arrangements and (i) overall decision making. People with mild cognitive impairment (MCI) can live independently; however, higher order abstract thinking is amongst the first abilities to diminish and may go unnoticed for a period of time. For instance, one study indicated that financial capacity is diminished in older people with mild cognitive impairment in the year before diagnosis of Alzheimer's disease (Triebel et al. 2009). Consequently, the use of screening for financial capacity of adults at risk is useful in the context of a multi dimensional assessment, such as in the Semi-Structured Clinical Interview for Financial Capacity (SCIFC) (Marson et al. 2009), Martin et al.'s (2008) domains of assessment or the informal assessment to probe for potential financial impairment or vulnerability (Widera et al. 2011). Such screens examine executive functioning related to financial capacity and can aid health practitioners' assessment of this important aspect of autonomy. If there is evidence of impairment in financial capacity, practical steps can be taken to promote financial protection. One of the most vital of these steps in FA is to have expert assessment whether the person has the ability to understand the consequences of the transaction.

8.5.3 Culture, Race and Elder Abuse

Some studies have examined FA in relation to racial and cultural background. Culture has an impact on values and beliefs and therefore inevitably on what behaviors are accepted, and those which are not. For example, a collectivist approach (generally seen in Eastern countries as opposed to an individualist approach generally seen in Westernized countries) could justify the use of an older person's finances and assets for the greater good of the family/community. Moreover, in South Africa, there is a moral pressure (by both family and state) to share pensions with family (Lloyd-Sherlock et al. 2018). Wainer et al. (2011) also point out that women within many Eastern countries experience economic dependency on men and may be expected to hand over any income to their husbands or other male figures when their husbands die, which may be interpreted as FA in Western culture. This can be underpinned by historic influences; for example, witchcraft laws from 1925 still exist in Kenya and have been used to justify both physical violence and the acquisition of finances and land of older people (Aboderin and Hatendi 2013). Equally, the English custom of primogeniture, where the first-born male child had a right to inheritance may also have legacy issues as the perception of family entitlement to the assets of the older person is considered an overwhelming contributing factor to financial abuse.

Acknowledging this, it is also important to understand that such homogeneous values should not be taken for granted within cultures. The evidence of culture as a risk for FA is mixed, with most studies occurring in the United States. Acierno et al. (2010) did

not find any statistical significance in rates of FA related to race, however, immigrant groups, such as Koreans and black older people have demonstrated a higher prevalence in an earlier study (Hafemeister 2003). Laumann et al. (2008) reported that African Americans were more likely to report FA than Caucasians, while Latinos were least likely to report FA. In a study based in Pennsylvania, Beach et al. (2010) found that the prevalence of FA in older African Americans was three times higher than non-African Americans (23% as opposed to 8.4%) and the risk for FA in the previous 6 months was estimated as eight times higher for African Americans than non-African Americans. However, separate studies identified Caucasians as being at highest risk of FA (NCEA et al. 1998; Choi et al. 1999).

An Australian study (Wainer et al. 2011), found that culture, race and language proficiency impact on money management and awareness of FA. For example, older people who described themselves as being from a Greek, English or Italian origin, regularly used wills and power of attorney, while this was not a common practice for older people from Vietnamese origin. In addition, Greeks and Italians were more likely to seek financial advice from legal sources, while non-English speaking participants used services such as banks for support. Essentially, Wainer et al. (2010) argue that understanding the fundamental values in relation to culture, race, family and finances underpins the responses to FA and this provides important pointers for targeted service intervention and risk analysis. Certainly, the way FA is understood is implicitly intertwined with cultural values and beliefs and this has had an inevitable impact on reporting, detection and intervention.

8.6 Quality of the Relationship

The quality of the relationship between the older person and the perpetrator is important to consider, taking in to account issues of culture, lifelong interactions and individual perspectives. For example, family relationships may have improved in recent times or deteriorated or relatives may be more or less involved in older person's life at particular times. Relationships may also be influenced by the perpetrator's financial dependence on the older person (MetLife Mature Market Institute et al. 2011). This may be a particular issue if the perpetrator is unemployed, has a mental health issue, gambling or substance abuse dependency (Rabiner et al. 2005). The older person may feel powerless to discontinue this negative relationship due to fear, kinship bonds, a justification of the FA due to his/her dependency on the perpetrator, or a threat of being abandoned or being admitted to residential care. They may also feel powerless to discontinue this negative relationship due to fear, kinship bonds, a justification of the FA due to his/her dependency on the perpetrator. Financial abuse may be committed by anyone but a trusted family member is often the most common perpetrator (Naughton et al. 2010). Within family relationships, studies demonstrate that the most common single perpetrator of FA is the older person's child (Laumann et al. 2008). As indicated previously, a common perception by children is an entitlement to the older person's assets, due to inheritance

rights, kinship ties or that the older person can simply afford to lose/give away the money or property (O'Brien et al. 2011; Conrad et al. 2011; Phelan 2013). Thus, the older person's assets may be considered to 'belong' to the child/relative and any awareness of actual FA by the perpetrator may be minimized or rendered invisible.

With regard to scams, the relationship is new and the older person is lured via the promise of some desirable advantage. This may be money, a gift, continued communication but these are either not received or when received are of little relative value compared to the financial transaction. Often, scams are constructed in such a way that there is hidden 'small print', 'too good to miss' advantages, and may also involve false copies of real institution documentation/websites. It is the believability and apparent genuineness of the scam agents that underpins the older person's propensity to part with money or other assets. A recent review by Burnes et al. (2017) suggests that 1 in 18 cognitively intact older people living in the community may be vulnerable to fraud and scams. After being lured in, it can be impossible to recover such financial outputs.

8.7 How the Relationship Is Rendered Exploitative

In many cases, FA is the result of a relationship gone wrong or where trust is betrayed (Wilber and Reynolds 1996; SCIE 2011a, b; Phelan et al. 2018). FA may occur over a gradual period of time, be recurrent or isolated and is generally shrouded in secrecy and deceit, and can be mostly associated with family FA (Mansell et al. 2009). Kemp and Mosqueda (2005) suggest that FA can involve the lack of business ethic, as there may be no written agreement, no ability to reverse a decision, a lack of full disclosure and a lack of validation of financial capacity to consent. It can be very difficult to distinguish, particularly as there may be no visible signs of its perpetration (Choi et al. 1999). Issues such as the perpetrator's 'intent' and the blurring of appropriate and exploitative use of finances may also complicate the discovery of FA (Choi et al. 1999). Furthermore, the perpetrator may have believed that he/she was justified in their actions or such actions may progress from supportive to abusive (Smith 1999). The perpetrator may rationalize the expenditure or removal of funds, which may, on the surface have the adult at risk's assent, but deeper examination can reveal a lack of consideration of consequences of transactions. Moreover, Conrad et al. (2011) and King et al. (2011) suggest that legislation which correlates nursing home payments with an older person's assets may also be used to justify the 'transfer' of monies, in order to escape payment.

Even when the older person is aware of the occurrence of FA, he/she may not disclose it and this may only be discovered when the person engages with safeguarding services, dies or is left penniless. The reasons for non-disclosure vary. The older person may have an irrational trust (Tueth 2000) in the perpetrator and feel helpless to refuse any demands (Rabiner et al. 2005) or be intimidated to agree to FA acts (Kemp and Mosqueda 2005). Non-reporting may also be due to embarrassment, particularly as many perpetrators are family members or considered 'trustworthy'

people (Conrad et al. 2010). In addition, a fear of losing independence, not being believed and both physical and cognitive challenges may prevent the reporting of the abuse (Rabiner et al. 2005). Conversely, the older person may think that the way to sustain the relationship is to endow the perpetrator with gifts, while the perpetrator may have signaled an expectation of such gifts. This context represents an exploitative emotional relationship resulting in FA. Furthermore, if the older person experiences poor family support and limited social contact, this can impact on the potential to detect FA and also reduce access to helping mechanisms (Naughton et al. 2010), although Acierno et al. (2009) demonstrated that older people who use social services were more at risk of FA, despite the increased potential for detection.

8.8 Consequences of Financial Abuse

There are significant consequences for older people who have been financially abused. Financial insecurity has a negative impact on health status (Bisgaier and Rhodes 2011; Burnett et al. 2016) and can lead to depression, stress, a compromised independence, social isolation and the loss of human rights and dignity (MetLife Mature Market Institute et al. 2011). In addition, unlike other cohorts of the population, older people do not have the same capacity to generate substitute incomes. For example, employment may be more difficult or even impossible to secure and older people have limited methods of generating alternative funding sources (Nerenberg 1999; Smith 1999). The older person may have to turn to other family members for support, which can increase stress within the family. Furthermore, there may be other related effects on society. For instance, FA of an older person may create an increased financial dependency on government welfare systems and social services (Setterlund 2001; SCIE 2011a, b) while abuse itself has been linked to higher rates of hospitalizations and care services (Dong and Simon 2013).

8.9 Responding to Financial Abuse

Responding to FA of older people is a multifaceted challenge which demands an ecological approach (Bronfenbrenner 1979) encompassing micro, meso, exo and macro levels, (O'Donnell et al. 2015). Micro levels focus on the relationships within the immediate environment of the person; the meso level represents the interactions between the micro-level systems such as social networks; the exo level refers to interventions which impact the adult at risk but do not directly involve them, such as the legal system, the economic system while the macro system relates to the broader cultural domain of the over arching beliefs and values of a society (see O'Donnell and Phelan in this book). For example, on a macro-level, a major aspect of addressing FA is to change perceptions of older people in society.

Ageist stereotypes contribute to constructing older people as being unable to manage their own affairs, having lesser needs and rights than 'normal' society and having lesser value in society. Even, in the event of reduced financial capacity, societal perspectives need to promote a discourse which clearly identifies that finances are not transferred to another person, but are *managed* with the best interests of the adult at risk (who always retains ownership). Changing attitudes and culture represent a major goal in the prevention of financial abuse. Four major areas for protecting from financial abuse are safeguarding legislation, safeguarding in financial institutions, specialist multi-disciplinary teams and money management programs. Other responses are covered in a separate chapter in this book based on empowering older people to protect themselves from financial abuse (see O'Donnell chapter in this book).

8.10 Detecting Financial Abuse, Legislation, Policy and Practice

8.10.1 Detecting Financial Abuse

Detection is complicated by a lack of knowledge and specific FA training of staff (health and social care, legal personnel, banking staff) as targeted questions may not be asked and warning signs not recognized (Rabiner et al. 2005). In particular, it has been shown that older people are considered 'low risk' targets for FA, due to poor reporting patterns. There is also a reduced likelihood of reporting as the older person may fear being perceived as loosing cognitive function and even when the crime is reported, there may be problems with memory pertaining to the precise details of the incident(s) (FBI 2013). Consequently, early and adequate detection of FA is fundamental to addressing the issue.

Due to the covert nature of FA, enabling detection is central to intervention. This involves a number of strategies. The process of screening is considered a fundamental, universal approach as an older person may not be aware of financial abuse and direct questions have the advantage of revealing possible dubious financial practices (Reeves and Wysong 2010). Clinicians have a dual role in asking about changes in finance and any atypical expenditures. Moreover, clinicians may be asked to give expert witness regarding issues of mental capacity or vulnerability of the adult at risk to coercion. To date there is a dearth of screening tools specifically for financial abuse. The only known validated financial abuse screening tool in the literature related to vulnerable adults is the Older Adult Financial Exploitation Measure (OAFEM) (Conrad et al. 2010), which is comprised of 25 questions and has been shown to heighten a suspicion of financial abuse (Phelan et al. 2014). Essentially, any screening for financial abuse should be incorporated into the general assessment and interaction with the adult at risk to normalize the process and reduce anxiety (Reeves and Wysong 2010).

8.10.2 Legislation

Legislation for older people who experience decision-making capacity challenges demands a focus on functional capacity and the preservation of authentic consent and autonomy. There are various legal protective interventions which can assist with financial management such as power of attorney, guardianship or decision making representative. However, the regulation of the guardian's activities is fundamental to protecting finances and maintaining good practice (Setterlund et al. 2007). Consent of an older person to sign over ownership of property may, on the surface appear to be a simple activity, but it is necessary to examine the consequences of such an action and who benefits from this. Other related principles are those of undue influence and unconscionability. Undue influence may be defined as inappropriate or excessive manipulation of the older person, and is a major strategy used to gain access to the assets although it can be challenging to identify cases where psychological pressure has been applied to sign apparently legitimate documents (Wilber and Reynolds 1996; Gibson and Honn Qualls 2012). Thus, assets are transferred during a period of vulnerability. Closely related to the principle of undue influence is the principle unconscionability. This involves an action that is detrimental to the older person due to an imbalance in bargaining power. Thus, unconscionable acts can include many aspects of FA, such as signing over property, funds and assets, particularly in the context of decision making capacity impairment.

8.10.3 Financial Agencies

Financial agencies are an important early intervention mechanism as they may be the first to detect irregularities in finances and are in a unique position to assist in protecting customers (BITS Fraud Reduction Steering Committee 2006). In addressing FA, research has increasingly emphasised the role of financial institutions (King et al. 2011; Phelan et al. 2018). This is particularly relevant as bank staff often experience a suspicion of FA of the older person (Phelan et al. 2018). Despite this, financial agencies, such as banks, post offices, credit unions and building societies may be reluctant to intervene in financial abuse of older people. Concerns regarding a breach of privacy, confidentiality of the client and defamation of the alleged perpetrator through reporting the suspected FA have all been identified (Choi et al. 1999; Hughes 2003a, b). It has been noted that having mandatory reporting for financial abuse has been challenging to financial institutions and voluntary reporting systems appear more acceptable (Hughes 2003a).

In the context of strategies which are used by banks, reporting programmes have been very effective in preventing financial losses (Hughes 2003b). Targeted education of front line staff and management can alert awareness and action by such staff in responding to suspected FA, for example, in the case of irregular banking documents, missing financial documents and unusual banking activities

(National Committee for the Prevention of Elder Abuse 2008). Moreover, as banking and money management become more sophisticated, older people may struggle to adapt to new methods of money management (Conrad et al. 2011). In an age of technology, new modes of contact (phishing, vishing, and scamming via the internet) can heighten susceptibility to FA (Crosby et al. 2008). Thus, ensuring equity through human interface is fundamental for people who prefer personal facilitation with banking activities.

8.10.4 Multidisciplinary Teams

The process of using multi-disciplinary teams to address the FA of older people is essential as a variety of diverse support and intervention mechanisms may be required (Kemp and Mosqueda 2005; Reeves and Wysong 2010). Such teams require elements of an inter-agency framework, a multi-agency management committee and policy and service audits to oversee the safeguarding service's coordination (Home Office and DoH 2000). Partnerships from diverse disciplines allow specific areas of expertise to generate comprehensive investigations, responses and general case management (Reeves and Wysong 2010) and some teams have incorporated the training of older people themselves as members of response teams (Response Technical Team) (Nerenberg 2008). More importantly, multi-disciplinary teams have been shown to increase prosecution rates for FA (Navarro et al. 2012). One example is the Financial Abuse Specialist Team (FAST) in California (Orange County), USA. This is a voluntary service which is comprised of diverse professionals such as adult protective services, law enforcement, legal representatives, financial planners and banking representatives. Each month, cases are reviewed and the varied disciplinary membership has the advantage of providing strategic plans to resolve financial abuse (Allen 2008). The FAST also provides specialist training for police and banking personnel. Despite its success, the establishment of such teams is limited beyond the United States of America.

8.10.5 Money Management Programmes

Money management is an essential component of independent living (Elbogen et al. 2011) and an important element in independent budgeting (Moran et al. 2013). Money management programmes have been used to combat financial abuse (Nerenberg 2008), particularly as adequate funds are necessary for basic needs such as food, shelter and so forth. An actual or perceived inability to manage money can provide a catalyst to involving a third party to manage financial affairs. Consequently, money management programs are particularly relevant for older people who have/or are perceived to be having challenges in financial capacity or are having difficulties negotiating new technologies regarding banking and financial affairs. Money

management programs can range from assistance with routine tasks such as paying bills to more complex tasks such as general budgeting and management of banking accounts, thus empowering the older person to monitor their funds (Setterlund et al. 2007). Enabling empowerment through money management programs may also be an important element within personalized budgets, as a cultural change may be required in relation to being transformed into a care purchasing consumer (Moran et al. 2013). Moreover, enabling a balance of risk is an important component of safeguarding and the management of personal budgets (Ismail et al. 2017). One notable innovation focused on empowering older people was undertaken by the National Centre for the Protection of Older People in University College Dublin, Ireland and resulted in a website resource to assist older people in areas such as bank accounts, making wills, capacity legislation and home security (see chapter by O'Donnell).

8.11 Conclusion

Prevalence studies demonstrate that financial abuse of older people is a significant public health challenge globally. However, defining the issue is problematic as there is no current universally agreed understanding. FA is immersed in taken for granted cultural assumptions, family ties, blurred perceptions regarding its boundaries as well as requiring a much greater level of inter-sectorial collaboration. Despite having a significant impact on health and welfare of an older person, financial abuse has, to date, been under-researched and the capacity to appropriately respond to it is lacking. It is important that additional research is undertaken in this complex area and that robust evidence based prevention and intervention inter-sector strategies are integrated into safeguarding older people against financial abuse.

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Chapter 9
Keep Control: A Co-designed Educational and Information Campaign Supporting Older People to Be Empowered against Financial Abuse

Deirdre O'Donnell

9.1 Introduction

Empowerment is understood as a psychological and social construct. It connects individual and collective well-being as well as social change with strengths and competencies, ecological resources, environmental helping systems and networks as well as direct collective action (Drury et al. 2005; Hur 2006; Zimmerman and Rappaport 1988). Empowerment encompasses an individual's self-mastery and their power to participate and to be involved in the life of their several communities (Rappaport 1995). This multilevel construct moves between and within individual, organizational and political levels of analysis. The Cornell Empowerment Group described a process model of empowerment by which an individual gains greater access to and control of valued resources (Cochran 1992). This concept of empowerment emerged from the economic transformations and social justice movements of the 1970s. As a result, the practical application of empowerment programs in the fields of community psychology and social work has been concerned with the distribution of power and access to resources which are valued by society.

The experience of aging has provided the focus for social and health sciences research concerned with demographic trends depicting an aging population and the social, economic, psychological and health resources necessary to enhance quality of life and well-being in later life (Low and Molzahn 2007; O'Donnell 2011; Steverink et al. 2001; Wiggins et al. 2004). Feminist gerontology highlighted a youth-oriented society, which, at best ignored the conceptual interrogation of aging, and at worst, sustained stereotypes and normative prejudice in marginalizing the old (Biggs 1999; Biggs and Lowenstein 2003; Calasanti 2003; Calasanti and Slevin 2006). This research indicated the necessity to interrogate concepts such as

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well-being, quality of life and empowerment from the perspective of older women and men. In this way, research can reflect upon the life course transitions and adaptations of older people in order to determine how older people may be empowered to optimize their resources to meet their priorities and needs and thereby sustain their well-being and life quality.

Older people's agency in the context of personal and environmental circumstances informed much research which investigated quality of life and well-being in later life (Higgs et al. 2003; Low and Molzahn 2007; Rozario et al. 2011; Steverink et al. 2001; Wiggins et al. 2004). Recognition of the role of agency in the optimization of resources and the prioritization and attainment of goals in later life has pertinence for interventions targeted at preventing and/or managing cases of elder abuse. Elder abuse is a complex and multifaceted phenomenon which presents ethical challenges and dilemmas for those managing cases of abuse to reconcile the autonomy and self-determination of clients with issues of capacity, risk, and vulnerability (O'Donnell et al. 2015a). In a study of self-determination in elder abuse, Bergeron (2006) argued that a social worker's role in managing a case of elder abuse is to facilitate appropriate decision-making of an older person by guaranteeing the availability of choices for intervention. Some of the mitigating factors described by Bergeron (2006) as impacting older people's decision-making included environmental and family circumstances, life course experiences, health, and cultural factors. The study underscored the availability of resources in cases of elder abuse which would provide realistic alternatives and facilitate an older person to choose a particular intervention to end circumstances of abuse.

Despite increasing recognition of the epidemic of elder abuse, there is a lack of robust evidence to support any particular intervention to prevent or address abuse (O'Donnell et al. 2015b). It is generally agreed that elder financial abuse is underreported and is particularly difficult to recognize or detect. This form of elder abuse is often concurrent with, and indicative of, other types of abuse particularly discriminatory and/or psychological abuse. Anand and colleagues (2011) undertook participatory qualitative research with older people in Ireland, in which they explored older people's understandings of abuse. The findings of this study indicated a new concept of 'personhood abuse', which referred to the effects of societal ageist attitudes on an older person's confidence, autonomy, and agency. The study highlighted abuse preventative interventions which addressed the repercussions of this attitude that included: awareness and information-raising, peer support, community engagement activities and enhancing personal, social and collective resources.

In summary, at the core of best practice interventions which seek to maximize older people's well-being and reduce their vulnerabilities to any form of abuse is recognition of older people's agency. Fostering and protecting the agency of the older person and empowering them to optimize their strengths and resources underscores best practice in social and health care interventions for older people (Mulligan et al. 2012; Shearer et al. 2012). These practices are informed by the necessity of optimizing strengths and resources to attain the goals and priorities of the older person. This strengths-based perspective is in line with conceptualizations of

empowerment as well as social-gerontological and feminist discourse, which are concerned with the redistribution of interpersonal power, social justice, and change.

9.2 Keep Control

This chapter provides a description of the *Keep Control* campaign. This intervention resulted from a process of authentic and meaningful collaboration between representatives of older people and academic researchers from the National Centre for the Protection of Older People (NCPOP) in University College Dublin. The project and intervention were funded by the Irish Health Service Executive (HSE). *Keep Control* is a strengths-based preventative intervention which celebrates, protects and fosters the agency and resources of older people. It supports older people to safeguard themselves from financial abuse.

9.3 Research Design

The Older People's Empowerment Network (OPEN) was established at the commencement of the project to co-design and develop the *Keep Control* intervention. OPEN is a network of representatives of older people and researchers who are engaged and involved with academic research related to the health and social well-being of older people in Ireland. The co-design approach adopted for this project adheres to principles of democratic active participation and dialogue in collaborative research (O'Donnell et al. 2016).

9.4 Co-design Collaborator Recruitment

Five collaborators were recruited to OPEN from the membership of Non Government Organizations (NGO) and community-based advocacy organizations working with older people. These were older people willing to share their expertise and knowledge in relation to the experience of aging. Two academic researchers (including a research assistant) also joined the team. An academic researcher co-chaired each of the co-design meetings with one of the older people representatives who were invited to co-chair on a rotating basis. The academic chair facilitated the collaborative work and acted as a point of contact for all co-design members.

The academic chair also convened a panel of nine advisors who had professional interests and expertise in vulnerable adult safeguarding as well as in financial protection. This included: two solicitors with expertise in relation to older person safeguarding and financial abuse; a member of An Gárda Síochána (Irish Police Force) with a specialist role in community policing and financial abuse prevention; two

members of the Irish state's Money Advice and Budgeting Service (MABS); the Health Service Executive's Dedicated Officer for the Protection of Older People; a senior social worker with a specialist role in adult safeguarding; a branch bank manager with an interest in adult financial abuse prevention and a member of the Health Services Executive's Services for Older People. These experts were invited to attend co-design meetings on a rotating basis to guide the collaboration and to share their specialist knowledge. Furthermore, they contributed to the intervention development by reviewing the intervention at the draft stage and providing feedback in relation to accuracy and accessibility. The advisors also provided access to resources for reproduction or assimilation into the intervention.

9.5 Designing Meaningful Collaboration

The methodological approach adopted for this co-design work was supported by five enabling factors ensuring democratic, meaningful and authentic public involvement (O'Donnell et al. 2016). These factors were:

1. engaging active participation from the earliest point possible in the process of intervention development;
2. establishing a co-design team (OPEN) with a critical mass of public representatives and which is organized in a non-hierarchical manner;
3. having a defined objective with designated deliverables which are discussed and agreed upon by the co-design team from the outset of project development;
4. ensuring there is adequate knowledge exchange between co-design members and ensuring that professional knowledge is transferred and disseminated throughout the team in an accessible way and finally;
5. activating the public representatives as the 'public faces' of the initiative for the purposes of implementation and dissemination.

9.6 Co-design Procedures

Eleven co-design meetings were held with the OPEN group between July 2013 and September 2014. These were structured collaborative workshops which ensured that the resulting empowerment intervention was person-centred, targeted to the needs and priorities of older people and accessible (Table 9.1). Detailed notes of each of the meetings were taken by a research assistant and disseminated prior to each workshop.

The first two meetings were designed a priori and were focused on capacity building for the team. The purpose of this capacity building was developing a common understanding of later life empowerment from which to collaboratively build the safeguarding intervention. It was important to center the collaborations on the

Table 9.1 Structural overview of the 11 co-design workshops

Workshop	Theme	Content
Workshop one	A-priory design for capacity building: Later life empowerment	Introductions, project familiarity and agreement of terms of reference for co-design participant roles and objectives. The academic chair presented a model of later life empowerment which was developed from previous inductive grounded theory analysis of focus group data collected from older people, NGO community advocates and representatives of older people as well as senior case workers responsible for managing cases of elder abuse. The co-design group discussed the conceptual model and identified the component elements and outcomes from empowerment. This provided a theoretical and conceptual background to the collaborative work.
Workshop two	A-priory design for capacity building: The voice of elder abuse survivors	The voice of elder abuse survivors was represented in the co-design group through a secondary analysis of qualitative data collected from semi-structured interviews with nine survivors. The qualitative data were re-analyzed using a coding framework representing the model of empowerment. The data was presented to the group in such a way as to describe the journey from abuse to survival. The group's attention was drawn to the interpersonal and intrapersonal resources for survival which were featured in the survivors' stories.
Workshop three	Resources for financial control (MABS)	Presentation from an expert advisor from the states money advice and budgeting service (MABS) followed by group discussion of the MABS resources in relation to financial safeguarding.
Workshop four	Review of legal aspects of financial abuse.	Presentation from legal expert advisor (former law reform commissioner) with a discussion of some recent legal cases. The discussion highlighted issues involved in the financial abuse of older people including undue influence and unconscionable bargains. There was also discussion of vulnerabilities posed by joint account banking arrangements.
Workshop five	Brainstorming the intervention	Brainstorming session with the group for planning intervention components. Identified core principles of the intervention as including: Retaining autonomy, staying in control, responsibility, respectful consultation. It was agreed the interventions should be targeted towards prevention.
Workshop six	Review of intervention exemplars. The perspective of a social worker on financial abuse of older people	Review of some existing interventions related to financial literacy (MABS), education and planning (think ahead, Teagasc), security (Garda – Public awareness campaign). The group discussed how the strengths of these interventions could be translated into the developing intervention. Presentation from a senior case worker responsible for managing cases of elder abuse. Discussion of the psycho-social aspects of financial abuse.

(continued)

Table 9.1 (continued)

Workshop	Theme	Content
Workshop seven	Mapping the intervention components	Mapping the proposed intervention content. Agreement on the topic areas for focus and the three intervention components (website, DVD and resource pack). In-depth discussion of the website layout and principles for design: Accessibility and user-friendly, colors and audio transcription for readability, positive images of older people in their everyday lives. Intervention text content was reviewed and suggestions for edits were made. Title of the intervention was agreed: Keep control
Workshop eight	Planning the DVD	Discussion of the DVD content and agreement on design principles. Target audience to be older people and will be delivered by older people talking directly to other older people. Review and agreement of the script.
Workshop nine	Reviewing the intervention text content (website and resource pack)	Review of the content for three of the intervention component areas: Opening a joint account, creating a will, assisted decision-making. Feedback to the group as to the review comments from the panel of expert advisors.
Workshop ten	Review of three intervention components	Review of the website with discussion and feedback on any suggestions for modification etc.
		Review of the draft videos for the DVD with feedback for final edits and revisions.
		Review of the information pack content including the toolkit resources with feedback for final edits and revisions.
Workshop eleven	Dissemination	Final review and feedback on the three intervention components. Agreement of the dissemination plan and intervention launch.

lived experiences of elder abuse survivors. Therefore, the capacity building also allowed for discussion of the intrapersonal and interpersonal resources for later life empowerment evidenced in the testimonies of survivors. The subsequent eight meetings were thematically organized; as per the requirements of the project and the agreement of the team members. Where relevant, advisors were invited into workshops to share knowledge and expertise (Table 9.1).

9.7 Results

Keep Control is a multi-media educational campaign which provides information to older people necessary for their self-protection from financial abuse. The campaign consists of three pillars for the dissemination of information and resources necessary for older people to safeguard their finances. These pillars are a website, a DVD and an information pack containing *Keep Control* resources.

9.8 The *Keep Control* Website

The Keep Control Website is the main access point to information and resources which enable older people to empower themselves against financial abuse. In addition, the video content that was developed for the campaign is embedded into the website. This content features older people empowering themselves in situations where they may be vulnerable to financial abuse by taking preventative measures. The website provides an outlet for community exchange of information and resources. It is connected to social media networking sites including A *Keep Control* Facebook and A *Keep Control* Twitter Account. These platforms allow older people and those interested in the campaign to engage with key issues and topics around elder financial protection as well as generating opinions and discussions around the topic.

The website follows guidelines for accessibility and disability access. This includes the use of high-contrast colors and an accessible font (Verdana). Furthermore, there is a large text option on the site which allows users to increase font size. There is also access and instructions for the use of open-source software, designed to enable users with a visual impairment to access web-content. The website contains photos in order to enhance its visual appeal. Many of the photos are of the actors who feature in the DVD thus creating consistency in terms of branding between the different formats of the intervention.

The content of the website has been structured in such a way as to enable users to navigate it using minimal scrolling. This is to ensure that the links outlining the flow of information are visible and easily accessible at all times. The user may access the main sections of the website through a tab bar which is located at the top of the webpage and which is visible on each page of the site. Each section is segmented into smaller units and subunits of information with their own individual page. The user navigates this information through a drop-down menu on the left-hand side of the screen while links to subunits are also displayed at the bottom of the page. At all times a breadcrumb trail appears horizontally across the top of the webpage, just below the main tab-bar. This allows the user to keep track of their location within the website and there are links back to each previous page the user navigated.

The homepage of the website contains a welcome section which introduces the *Keep Control* campaign and provides an overview of the site. A link to the Keep Control video content is available and can be accessed by clicking on a screen-shot. The video content is hosted off-site in order to ensure minimal disruption to the website which may be caused by storing large video/audio files. The information pack, including the tools and resources, which were co-designed for the campaign are also available to view and download from the site.

The website information includes a section on Financial Abuse which provides the user with a description of what financial abuse is, including the different types of financial abuse; warning signs of abuse; typical perpetrators and a discussion of what to do if one suspects financial abuse. The main intervention information

content is located in the *Keep Control* section of the website. This content is divided into five areas:

1. Making a Will
2. Enduring Powers of Attorney
3. Joint Accounts
4. Decision-making at Critical Life Events
5. Protecting myself on my Doorstep

Each of the five content areas is broken down into smaller units of information which provide information related to what each content element is and why they are being encouraged to safeguard themselves in relation to each element. Furthermore, they are provided with area-specific guidelines for empowerment and self-protection as well as warning signs of potential abuse which are specific to the content area. It was agreed by the OPEN co-design team that modeling appropriate language, behavior and dialogue would be important for enabling older people's empowerment. Therefore, each of the content areas included a sub-section called 'we need to talk: conversation tips and starters'. This sub-section included exemplary language and advice for conversation planning and preparation. For the most part, this advice was tailored to assist the older person to plan potentially difficult or challenging conversations in such a way as to minimize the risk of conflict. This was complemented by a content-specific video which was embedded into the website which modeled these conversations and dialogues.

9.9 The Keep Control DVD

The *Keep Control* DVD was developed by the OPEN co-design team as the second pillar of the campaign. It is composed of seven video segments each of which are embedded into the website to accompany the corresponding information (Table 9.2). The DVD was also included in the hard copy information packs. It features older people in five different scenarios where they are vulnerable to the risk of financial abuse. These scenarios correspond to the five content areas of the website. In these scenarios, the older person may be subjected to subtle intimidation, be placed under undue influence or may fail to take responsibility for their affairs.

The DVD shows an older person acting out two different endings in five different scenarios. In one ending the older person is empowered and self-protects from potential financial abuse by following the guidelines and recommendations outlined in the *Keep Control* campaign. In the other ending, the older person doesn't follow the guidelines and as a result, becomes vulnerable to financial abuse. The scenario pauses at the point where there is a potential for the older person to become vulnerable. At this point, the older actor turns to the camera and outlines the two options that he/she has. The viewer can then choose to select option 1 or option 2. If the viewer selects option 1, they will see the older person acting out one ending. If the

Table 9.2 Seven DVD content areas

Video Theme	Content
What is elder financial abuse? Keeping control of your finances	This is an introductory video which outlines what elder financial abuse is and gives examples of crimes and subtle forms of financial abuse. An example of financial abuse follows. This example shows an older woman being intimated by her son who appears to have a drinking problem and who takes her money without her permission and does not use it to benefit her. The closing scene of this video explains the aims and key messages of the keep control campaign and directs people to visit the keep control website to find out more information.
Making a will: Keeping control of your possessions	In this video, an older woman decides it's time for her to make her will and her son puts some pressure on her to see his solicitor. Option one shows her accepting her son's offer and the pressure she faces as a result. Option two shows her insisting that she see her own solicitor and demonstrates her protecting herself from abuse by recognizing and resisting undue influence and following the guidelines for making a will which include getting independent legal advice. It demonstrates the older woman negotiating the details of her will with her solicitor. The video closes with the older person giving advice to viewers on how to protect themselves when making a will and the important things to remember.
Enduring power of attorney: Keeping control of your decision-making	This video underlines the importance of setting up an an enduring power of attorney (EPA). This is a legal decree, set up by a person with decision making capacity to protect their will, preference, values and beliefs in the event he/she loses decision-making capacity and is unable to manage their affairs. The video also demonstrates the challenges that families may encounter when an EPA is not in place and a close family member suddenly loses decision-making capacity. In this video, an older man and his daughter talk about an EPA. His daughter thinks it's a good idea to set one up but the older man is not so sure. The video demonstrates two options. In the first option, the older man decides against setting up an EPA and later develops dementia which makes it very difficult for his family to manage his affairs. In the second option, the video demonstrates the older man going through the process of setting up an enduring power of attorney by meeting with his solicitor. The video closes with the older person giving advice to viewers on how to protect themselves when setting up an EPA and the important things to remember.
Opening a third party account: Keeping your finances secure	This video demonstrates the circumstances in which it may be appropriate to set up a third-party account and the best procedures to follow when doing so. In this video, an older man and his daughter think about how she could withdraw money from his account to help him with shopping. The older man finds out what they should do and suggests that the two of them visit the bank to find out more. Once there, the bank confirms that the older man can allow his daughter to access his account by making setting up a third-party account and making her an authorised signatory. The older man has two options at this point. Option one is to set up the account without giving any thought as to how he wants it to work thereby risking losing control of the account. Option two is to give instructions to the bank about how the third party account should work thereby allowing him to keep control over the account. The video closes with the older person giving advice to viewers on how to protect themselves when setting up a third-party account and the important things to remember.

(continued)

Table 9.2 (continued)

Video Theme	Content
Decision-making at critical life events: Keeping control at critical times	This video shows an older man who has been diagnosed with a terminal illness. The older man has two options in this video. One option is to take each day as it comes and not to plan ahead while the other option is to start to make end-of-life arrangements. The video demonstrates the importance of putting your affairs in order as soon as possible and in the closing of the video the point is reinforced by the actor who advises viewers about how to keep control at critical life events.
Doorstep security: Keeping control of your safety	The video underlines the importance of exercising caution with cold callers and highlights important checks which should be performed. The video depicts a cold caller calling to an older person's home. The caller claims to be from a charity and asks the older person for their bank details. The older person has two options. Option one show the older woman giving the caller her bank details without performing any checks. This places the older woman at risk of financial abuse. The second option shows the older woman performing checks to verify the caller's identification and calling the police upon discovering that the caller is not legitimate. The video closes with the older woman reminding viewers of the checks that they should perform to protect themselves on their doorstep.
What do I do if I suspect abuse?	This video provides information to viewers on who to contact if they suspect that they themselves, or someone they know, is being financially abused. The video directs the viewer to the keep control website as well as highlighting the HSE helpline number throughout.

viewer selects option 2, they will see the older actor acting out the other ending. The viewer will also be able to view both options to see different endings.

The idea of demonstrating two different routes or scenario endings was generated from discussions among the co-design group. It was agreed that pausing the video at a particular junction in the scenario, would emphasize to the viewer that there is often a decision point in which an older person can self-protect and demonstrate empowerment which may prevent their vulnerability to abuse. Furthermore, it was felt among the group that the videos would demonstrate the behaviors and language of empowerment for viewers thereby modeling the advice provided by the content areas of the website or information pack within specific contexts.

9.10 The *Keep Control* Information Pack

It was agreed by the OPEN co-design team that in order to maximize the reach of the *Keep Control* campaign an information pack would be developed providing a physical hard copy of the campaign material. This information pack complements the electronic content (website and videos) and ensures that the campaign reaches older people who are not familiar with accessing information online. The *Keep Control* Information Pack is the third pillar of the intervention and includes an information booklet, a DVD as well as physical copies of the campaign resources.

The *Keep Control* booklet corresponds directly to the website in terms of the structure and information content. The design of the booklet echoes the website and DVD in relation to logos, color scheme, images, and content. The booklet adheres to accessibility guidelines (font size, contrast etc.). There is an introductory section which provides an overview of financial abuse in general and this is followed by more detailed information on the five content areas as well contact information and advice for responding to suspicions of abuse.

Campaign resources which were developed by the OPEN co-design group in consultation with the expert advisory panel were included in the information pack. These resources are also available for downloading from the website. The resources include the *Keep Control* videos, a financial planning and budgeting guide, a safeguarding door handle promoting security in the home, a window sticker to prevent cold callers and scammers, a calling card to deter door-stepping as well as a poster and a campaign flier. The fliers and posters advertise the *Keep Control* campaign and direct people to visit the *Keep Control* website. The fliers also list the top ten tips for protecting oneself against financial abuse.

The budget planner facilitates older people in interacting with family members and/or other household members by providing them with a resource to ensure transparency and fairness in managing shared household expenses. The door handle can be placed inside an older person's front door. The handle provides space to record important phone numbers, including emergency contact details and provides reminders of the top tips for safeguarding from bogus callers. The purpose of the window sticker is to assist the older person (or any member of the public) to maintain their doorstep security. The sticker can be placed in the window at the front of the house notifying a caller that the person does not want cold callers and does not buy and sell on the door. It also tells callers that they must be able to present verifiable identification. Calling cards are also provided in the pack, these are intended to be used by the older person to manage cold callers to their door. On one side of the card, the older person is reminded of important things to remember when a cold caller comes to the door. On the opposite side of the card is space for contact details. The older person can hand this card to a caller and ask them to fill in their contact details. The card allows the older person to consider whether they wish to engage with the caller and if so they can be in control of how to initiate this contact.

9.11 Dissemination

The dissemination of the campaign commenced with an intervention launch by a Government minister with responsibility for disability, older people, equality and mental health. The OPEN co-design group was promoted at the launch as the architects of the campaign and the public faces for dissemination. This launch was complemented by a national 'roadshow' of seminars among local community groups, active retirement groups and other community-based support networks for older people. A total of 16 seminars were held across eight national regional departments.

The focus of these seminars was for the OPEN co-design members to disseminate the campaign and to train older people to facilitate the engagement of their community peers with the intervention content. This provided the basis for downstream cascading of the information through local champions. In addition, approximately 2000 information packs were disseminated to local libraries and community centers nationwide.

9.12 Discussion

Empowering processes are those actions and programs which enable people to gain control over valued social resources and to leverage those resource to make or influence decisions that affect their quality of life and well-being (Perkins and Zimmerman 1995). Previous research and theorizing from the fields of health psychology and community empowerment have indicated that successful empowerment processes facilitate community members to develop skills that increase their independence from professionals (Dowling et al. 2011). Empowerment processes targeting the wellbeing of older people should include the transfer of knowledge and skills for self-care and decision-making as well as the recognition and development of intrapersonal and interpersonal resources for optimizing well-being (Chapin and Cox 2002; Fisher and Gosselink 2008). The strengths-based perspective of the *Keep Control* campaign emphasizes the sources of life strength as well as capacities for resilience in later life rather than deficit management focusing on vulnerability or risk. In this way, the campaign is an empowering process which promotes the agency of older people and recognizes their abilities to safeguard their well-being through fostering their intrapersonal and interpersonal strengths.

A significant feature of the *Keep Control* campaign, which further characterizes it as an empowering process, is the involvement of community members in the development, implementation, and dissemination of the intervention. The process for co-designing the intervention was grounded in a partnership based on equality between target community members, academic researchers, and professionals. This participative process, by which target communities are encouraged to interpret their situations and identify the intervention outcomes, is noted as being critical to successful, meaningful and authentic empowerment (Chapin and Cox 2002; Fisher and Gosselink 2008). Designing meaningful collaboration in the co-design process was central to the success of the *Keep Control* campaign as it ensured intervention authenticity. Furthermore, it encouraged receptivity among the target community; it was an intervention for older people developed and delivered by older people. This was a central feature of the campaign dissemination which encouraged local *Keep Control* champions to disseminate the intervention content among their peers.

9.13 Conclusion and Limitations

The fostering of agency over valued resources is critical to a concept of empowered aging which seeks to promote active participation in processes of resiliency and self-protection. *Keep Control* is a resource for all older people living in Ireland and also for people interested in elder financial abuse protection. It provides information and resources to support older people to be empowered against financial abuse and/or exploitation. This is underscored by an understanding that empowerment occurs when an individual takes responsibility for their own protection by keeping control over their affairs and ensuring that their decisions, wishes, and intentions for their finances are respected and followed. The *Keep Control* campaign aims to empower older people with competencies, skills, and knowledge which facilitate choice, self-determination and assertive interpersonal interactions. In this way, an older person can open themselves to processes of empowerment in safeguarding their finances and their well-being in later life.

9.13.1 Limitations

Capacity building and the empowerment of elder abuse survivors to engage with academic research and intervention co-design is necessary. The requirement to build capacity for meaningful, empowering and democratic participation mitigated against the inclusion of elder abuse survivors on the co-design team for this study. A decision not to include those with direct experience of elder abuse was taken out of consideration of the potential to do harm. This harm could arise from repeated retelling or reliving of their abuse story. However, the lack of survivors' voices in co-design team is a considerable limitation of the study. This was offset through the inclusion of a secondary analysis of qualitative data collected from nine survivors which was presented to the co-design team. The purpose of this analysis was to center the co-design work on direct experiences of surviving abuse and was presented through the lens of empowerment theory.

Sustainability of the campaign beyond the lifetime of the project funding is a challenge and a further study limitation. This has been offset by the development of the OPEN co-design team who have continued to engage with the intervention content and dissemination. Furthermore, the dissemination of the intervention encouraged the development of local and regional *Keep Control* champions nationwide. However, ongoing coordination of the dissemination activities and maintenance of the online content in the absence of sustained funding continues to be a challenge. This challenge can only be offset through the commitment of organizational and policy leaders as partners with regards to intervention maintenance and dissemination.

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Chapter 10
Elder Abuse and Dementia

Claudia Cooper and Gill Livingston

10.1 Introduction

Globally, about 47 million people were living with dementia in 2015, and this number is projected to triple by 2050 (Livingston et al. 2017). People with dementia are particularly vulnerable to abuse (McCausland et al. 2016), probably because they are more likely to depend on others for care, and to have impairments in memory, communication abilities and judgment that make it more difficult for them to avoid, prevent and report abuse. Many are reluctant to report abuse perpetrated by those on whom they depend. Because people living with dementia are less able to care for themselves, they are also more at risk of self-neglect, which is defined as elder abuse in some jurisdictions, including the USA (United States of America). In a study of USA Adult Protective Services (APS) cases, cognitive impairment was significantly associated with self-neglect in older people (Choi et al. 2009). Ninety percent of patients with dementia develop neuropsychiatric symptoms at some point in the illness (which include agitation, aggression, depression and apathy) (Ballard and Oyebode 1995), and these symptoms are associated with an increased risk of abuse, probably because it is more difficult to care for a person who is experiencing them. The consequences of abuse include distress, physical and mental ill-health, hospitalization, reduced survival, institutionalization and financial loss (Dong and Simon 2013; Dong et al. 2011, 2013). People with dementia are probably particularly vulnerable to these adverse consequences, because they already have worse physical and mental health, and are at greater risk of mortality, hospitalization and institutionalization.

In this chapter, we will first discuss the particular challenges of detecting abuse in people with dementia. We then review the evidence regarding the prevalence of elder abuse in people with dementia and discuss possible risk factors for it, before

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exploring what we know about how to reduce and prevent abuse in this population. The people with dementia that have contributed to the research studies presented had by definition, received a dementia diagnosis and the opportunity to take part in research. People from marginalized groups, including those living in areas of deprivation and who are from Black and Minority ethnic groups, are less likely to be diagnosed and to take part in research; so these groups may be relatively less represented in the evidence base presented (Cooper et al. 2014; Cooper et al. 2010a, c). The act of abuse does not imply intent, and in many cases the carers may not have viewed their own actions in this light.

10.2 Detecting Elder Abuse in People Living with Dementia

Estimates of the prevalence of elder abuse are likely to be influenced by the inability of many people with dementia experiencing abuse to remember and report it, and the fear and embarrassment they may experience in doing so. A wide range of prevalence figures are reported in people with dementia, possibly because of the different populations studied and the methods used to measure abuse (Cooper et al. 2008a; Dong 2015). While health care professionals who suspect or have evidence of abuse will ask people with dementia for their perspective of whether they feel safe, or have fears, or recall abuse and many people with dementia can give an at least partial account of their experiences, we have limited evidence about how many people with dementia would report abuse if asked. Only one research study, to our knowledge has asked older people with dementia to self-report abuse. In a USA study involving 254 family carers and 76 older people living with dementia, 17.2% of carers reported perpetrating violence, and 26.1% of older people reported experiencing violence (Vandeweerd et al. 2013).

In clinical practice, abuse is generally detected by staff working with older people asking about it directly, and being alert to possible signs of abuse such as fear, an older person appearing to lack basic necessities or having unexplained bruises. Research studies have made a case for screening people with dementia for abuse in clinical services, through routinely asking family carers, and people with dementia if they are able (Cooper et al. 2009a), but this does not happen routinely in practice in most settings. Some studies have used a vignette about a fictional person with dementia being cared for by her son who uses a range of care strategies, some of which met widely accepted definitions of abuse. They have demonstrated that professionals, family carers, home carers, medical students and other professionals frequently do not agree about what constitutes abuse. For example, locking the person with dementia in the house all day while her son went to work, would universally be considered abusive in policy, because it would not be the least restrictive option to keep her safe and she would be unable to get out in an emergency; but many of the respondents in the research studies did not agree this was abusive (Caciula et al. 2010; Hempton et al. 2011; Selwood et al. 2007; Thompson-McCormick et al. 2009). Only a third of health care professionals working with older people reported

that they had detected a case of elder abuse in the last year (Cooper et al. 2009b). Around a quarter of vulnerable older people report abuse when they are asked about it (Cooper et al. 2008a). Together these findings suggest that detected and reported abuse cases are probably the tip of the iceberg.

Abusive behavior exists on a spectrum and the level of abusive behavior that puts a person at risk of significant harm and therefore requires reporting to the appropriate authorities requires careful consideration of contextual factors. The capacity of the person with dementia to decide whether or not to accept help should also be carefully considered. Where a person with dementia has capacity to make the decision about continuing in an abusive relationship or situation, professionals should carefully consider how to mitigate risks as far as possible, for example, through regular review (because dementia is a degenerative condition) discussing ways of coping with the person who is abusing and delineating clear, simple processes for accessing help. People with dementia with capacity will nonetheless be vulnerable and the likelihood that a decision to decline help was made under duress, and the possibility that other people may be at risk from the abuser must also be considered.

10.3 Prevalence and Risk Factors of Abuse in People Living with Dementia in the Community

A systematic review of six studies reported the overall past year median prevalence of physical and psychological abuse towards people with dementia as 11% and 19%, respectively (McCausland et al. 2016). Of the six studies surveyed, five used carer reports and one an objective measure of abuse. These objective measures of abuse, which look for signs of abuse such as a person being fearful, or having cuts or bruises, are less sensitive than self-report measures (Cooper et al. 2008a). In the carer-report study rated as highest quality, family carers of people with dementia referred to older people's mental health team services in London (UK) and the surrounding area were interviewed. Nearly half of the carers reported an abusive act(s) over the last 3 months, using the Modified Conflict Tactics Scale, and a third reported that abusive acts were happening "at least sometimes" (Cooper et al. 2009a). In the study that used an objective measure of abuse, which was rated as being of higher quality, Friedman et al. (2011) analyzed cases of physical abuse and matched controls admitted to trauma centres. Dementia was more common among cases where elder abuse was suspected compared with controls (Friedman et al. 2011).

A couple of large studies have used the Minimum Data Set for Home Care (MDS-HC) abuse screen, an objective measure, to report correlates of abuse in people receiving home care services. In the largest European survey of home care recipients to date (4000 people aged 65+ receiving health or social community services) those screening positive for abuse were more likely to be cognitively impaired, depressed, to have delusions, and to be actively resisting care (Cooper et al. 2006). In a study which used this screen with 701 people aged 60 and older seeking home and community-

based services in Michigan between November 1996 and October 1997, participants' alcohol abuse, psychiatric illness, and short-term memory problems were significantly associated with the signs of potential elder abuse (Shugarman et al. 2003).

In a systematic review of studies involving people with and without dementia, elder abuse has been consistently linked to greater impairments in cognitive and physical functioning, and with behavioral and psychological symptoms. It has also been associated with fewer social protective factors, such as, lower social support, socioeconomic disadvantages and being from a minority ethnic group (Dong 2015). In a study that explores risk factors for abuse reported by family carers towards people with dementia, more anxious and depressed carers reported perpetrating more abuse; this relationship was mediated by using dysfunctional coping strategies and higher burden. Abuse was also predicted by: spending more hours caring, experiencing more abusive behavior from care recipients and higher burden (Cooper et al. 2010b).

10.4 Prevalence and Risk Factors of Abuse in People Living with Dementia in 24 hour Care

One third of UK people with dementia live in care homes and at least two thirds of care home residents have dementia (Knapp et al. 2007). Most care home residents have dementia and rely on others for personal care and many exhibit challenging behaviours, factors associated with higher risk of abuse (Cooper et al. 2008a, b). Carer stress in home staff is associated with: low job satisfaction, long hours, low pay, physical demands, staff shortages and minimal education and training (Cohen and Shinan-Altman 2011; Castle et al. 2015) and lower empathy which may be linked to lower care quality (Astrom et al. 1990). As has been observed in family carers, experiencing violence and aggression from people with dementia may predict acting abusively, if staff react defensively or find managing aggression stressful. This could explain why people with dementia who have more neuropsychiatric symptoms are at increased risk of abuse (Cooper et al. 2010a). In addition, while family relationships may be difficult and challenging, the family member caring usually has a knowledge and understanding of the person with dementia that predates the dementia and frequently a loving relationship. By contrast, the professional carer may only have known the person since they developed dementia, and thus may have less understanding of the person behind the illness. This can contribute to a decrease in empathy and respect for that person's humanity, thus removing social and emotional barriers to acting abusively.

To find out more about the situations that arise in care homes which may be linked to abuse, researchers held qualitative focus groups with 36 care home workers that looked after people with dementia in London. The participants reported that situations with potentially abusive consequences were a common occurrence, but deliberate abuse was rare. They gave examples of common potentially abusive or neglectful situations: residents waited too long when asking for help for personal care, or were denied care they needed to ensure they had enough to eat, were moved

safely or were not emotionally neglected. Some care workers acted in potentially abusive ways because they did not know of a better strategy or understand the resident's illness; care workers made threats to coerce residents to accept care, or restrained them; a resident at high risk of falls was required to walk as care workers thought otherwise he would forget the skill. Most care workers said they would be willing to report abuse anonymously (Cooper et al. 2013).

Professionals working with people with dementia have reported high rates of abusive behavior. In one survey, a quarter of relatives of care home residents reported incident(s) of physical abuse (Schiamberg et al. 2012). In a study that used a valid and reliable measure to examine elder abuse by professionals, 16% of a random sample of nurses and care attendants who had been working at one of several long term care facilities in Taiwan for 6 months or longer, reported committing significant psychological abuse (Wang 2005). Other studies have shown that approximately 80% of nursing home staff have observed abusive behavior in the last year (Pillemer and Moore 1989) but only 2% of these cases are reported to the home management (Jogerst et al. 2012). This suggests that, unsurprisingly, professional carers are reluctant to report abusive acts, probably because doing so would have potential adverse legal, employment and social consequences.

Because of this, recent surveys have elicited care worker experiences anonymously. In an Israeli study of 510 care staff completing an anonymous questionnaire, just over half admitted abuse and 70% had witnessed maltreatment in the past year; more abuse was reported by staff who experienced more burnout and worked in larger facilities with higher staff turnover (Natan et al. 2010). In a small UK survey in 5 nursing homes, most respondents (n = 138, 88.5%) reported witnessing or suspecting abuse in homes where they had previously worked (Moore 2017). In both these surveys, staff were asked to identify incidence of 'abuse' or 'maltreatment', so behaviors not identified correctly as abusive actions were undetected. However, many professionals do not correctly identify abusive behaviors (Selwood et al. 2007).

In the largest UK survey of abuse in care homes to date, 1544 staff in 92 English care home units completed a revised version of the Modified Conflict Tactics Scale, adapted to include specific abuse and neglect items care workers had identified in previous, qualitative research (Cooper et al. 2013). Unlike in previous surveys, care workers were not required to identify whether behaviors occurring were abusive or not. They were asked how frequently a series of positive and potentially abusive behaviors were happening (to their knowledge) in the care home. 763 (51%) of care home staff reported carrying out or observing potentially abusive or neglectful behaviors at least sometimes in the preceding 3 months; and some abuse was reported as happening 'at least sometimes' in 91/92 care homes. Neglect was most frequently reported and the most commonly reported neglectful behaviors were: making a resident wait for care (26%), avoiding a resident with challenging behavior (25%), giving residents insufficient time for food (19%), and taking insufficient care when moving residents (11%). In contrast, only 1.1% of staff reported seeing or perpetrating physical and 5% verbal abuse. More staff reported abusive or neglectful behavior in homes with higher staff burnout-depersonalization scores on the Maslach Burnout Inventory. The authors concluded that anonymous reporting of abuse by care home workers is acceptable and feasible, and it could be useful indicator of care home quality (Cooper et al. 2018).

The best available evidence for institutional characteristics associated with abuse comes from inquiries conducted into abuse scandals. Prominent inquiries include an investigation into physical mistreatment of older people who were mentally frail by staff at Beech House in London, UK, over a 3-year period (1993–1996) (Trust 1999), and more recently Orchid view care home, where neglect was found to have contributed to deaths of five residents (Commission 2014). Common factors in these and other serious case reviews included: a poor and institutionalized environment; inadequate staffing levels, high use of bank and agency staff; little staff development and poor supervision; a lack of knowledge of incident reporting; closed inward looking culture; weak management, low staff morale and lack of involvement by relatives in care delivery, decision making and evaluation of service.

10.5 Interventions to Reduce or Prevent Elder Abuse

Measuring abuse is necessary to develop interventions to reduce it, but there are ethical dilemmas regarding how to manage concerning cases detected, or in deciding to measure abuse anonymously so they cannot be managed. Most abusive behaviour happens when quality of care is poor and carers, family, or professionals do not have other strategies to manage difficult situations. Abuse is sometimes, but rarely, sadistic. Encouragement of naming and reporting of abusive behavior is an important first step to reducing it. Management of the most serious cases of abuse, including financial abuse, physical violence, and occasionally murder, involves criminal justice systems. National legal frameworks for managing abuse vary; in California, medical professionals have been criminally charged and sentenced under elder abuse laws for the illegal chemical restraint (medication for the sole purpose of sedation) of patients (Livingston et al. 2017). We discuss below the limited evidence base regarding how to reduce and prevent abusive behaviours towards people living with dementia.

10.6 Preventing Abusive Behavior by Family Carers

A recent Cochrane review reported only one study that sought to reduce the occurrence of elder abuse in people living with dementia by addressing underlying risk factors (Baker et al. 2016). This study found no evidence that the START (STrAtegies for RelaTives) intervention, a manualized coping-based intervention which reduced carer anxiety and depression, also reduced their reported abusive behavior. For ethical reasons, the study team frequently intervened to manage concerning abuse reported in both groups, which may have masked an intervention effect. The researchers found that abusive behaviors decreased in carers in the intervention and control groups (Livingston et al. 2014; Cooper et al. 2015).

10.7 Preventing Abusive Behavior by Professional Carers

10.7.1 Increasing Knowledge, Awareness and Reporting

In a systematic review, four of the five studies that sought to reduce psychological abuse by paid carers through education, communication training and support did so significantly, although only one was a randomized controlled trial and was thought to be potentially contaminated. The review also identified two studies that had sought to increase the frequency of abuse reporting or assessment. The first found a non-significant increase in elder abuse reports in Japan after introduction of the elder abuse prevention and caregiver support law; the second that an educational intervention did not significantly increase the proportion of clinicians routinely assessing for abuse, although abuse status was more frequently charted (Ayalon et al. 2016). In two UK studies involving psychiatry trainee doctors and multidisciplinary mental health care teams, brief, knowledge-based interventions increased understandings about how to detect and manage abuse and there was an indication this may have led to an increase in reported abuse (Cooper et al. 2012, Richardson et al. 2002).

10.7.2 Reducing Physically Restraint

Several interventions trialed in research studies have sought to reduce use of physical restraints, such as bilateral bed rails, belts, and fixed tables in a chair, in institutional settings (Ayalon et al. 2016; Cooper and Livingston 2016). In most jurisdictions, use of restraint is subject to legal safeguards. While any unnecessary restraint is considered unacceptable, opinions about the relative harms of using sedating psychotropic medication or physical restraint to manage behavioral disturbance that may otherwise cause harm vary between countries. Some describe the use of psychotropic drugs in this context as chemical restraint, although this medication may be given to treat an underlying problem rather than to prevent the recipient's movement. In the UK, physical restraint is only legally acceptable if the person is likely to suffer harm unless proportionate restraint is used, and it is the minimum amount of force for the shortest time possible (Mental Capacity Act 2005). No UK research studies have included physical restraint as an outcome, probably because no level of ongoing physical restraint would be considered acceptable. By contrast there has traditionally been a preference for use of seclusion and physical restraint over chemical restraint in the Netherlands, although this is changing (Steinert et al. 2014). Interventions to educate front line staff about harms caused by physical restraint, and teach alternative, person-centred care strategies successfully reduced physical restraint (Ayalon et al. 2016). Similar programs have been successful in reducing antipsychotic use in care homes (Fossey et al. 2006).

10.8 Conclusion

People living with dementia are at increased risk of elder abuse. Family carers of people with dementia often report acting abusively when asked. Those caring for people exhibiting challenging and aggressive behaviors, who are caring for more hours and are experiencing high carer burden are most likely to act abusively. Abusive and neglectful behaviors have been reported in most care homes where research studies have studied this through anonymous reporting, suggesting that widespread introduction of anonymous reporting should be considered in care homes. In professional carers, experiencing burnout appears to be an important predictor of acting abusively.

While the high prevalence of abuse in people with dementia indicates a pressing need for strategies to reduce and prevent it, the only elder abuse interventions for which there is good evidence of efficacy in people with dementia target use of physical restraint, and were developed in countries where restraint is acceptable in some circumstances (Ayalon 2015). There are no interventions known to effectively reduce other abusive behaviors, partially due to difficulties measuring outcomes that paid carers are unwilling and residents with dementia unable or unwilling to report. Future interventions to reduce abusive behavior by professional carers should focus on reducing staff burnout and depersonalization; introducing true person-centred care by encouraging staff to explore residents' personal histories, current and past interests and build pleasant interactions into care, as well as reducing objectification of residents would from our findings, be rational strategies. The current limited evidence base regarding how to reduce family carer-perpetrated abuse towards people living with dementia would suggest that development and trials of a coping-strategy-based intervention that specifically targeted abusive behavior would be a rational next step.

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Chapter 11
Elder Abuse in the LGBT Community

Gloria M. Gutman, Claire Robson, and Jennifer Marchbank

11.1 Introduction

Though a great deal has been written about elder abuse in the mainstream population, most of it has failed to consider how, how often, and how differently, abuse manifests in the Lesbian, Gay, Bisexual and Transgender (LGBT) community; moreover, specific studies of elder abuse in the LGBT community are 'practically non-existent' (Cook-Daniels 2017, p. 543). These deficits are all the more troubling in light of Harrison and Rigg's (2006) suggestion that elder abuse is one of the most urgent issues to be addressed in the gay, lesbian, bisexual, transgender, and intersex population. Clearly, we don't know enough about LGBT elder abuse, but what we do know is that any differences between LGBT elder abuse and elder abuse in the general population have been predicated and generated (at least partially) by the cultural context in which they have emerged. In this chapter, we discuss some of the cultural differences and social perspectives that have influenced the LGBT population and consider how these might impact research, outreach, and initiatives designed to address the issue.

As Westwood (2018, pp. 3–4) has pointed out:

> …the abuse of older people involves at its heart, an imbalance of power relations.

In the case of older LGBT victims of abuse, these power relationships are strongly influenced by both historic and current factors, which not only include cultural attitudes, legislation, and social policies, but also how these have been perceived by people who identify as LGBT. For these reasons, we will stress the value of involving LGBT participants in processes and discussions, not just as an afterthought, but as an integral part of policy and program design. We illustrate and centre our argument in our experience of one co-led project: *Raising Awareness of LGBT Elder*

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Abuse conducted by the authors in Greater Vancouver, Canada, in 2015. This small project, though modestly funded and brief in duration, generated considerable interest from service providers and some positive changes in terms of awareness raising and police, institutional, and home care provider training. We suggest that its success is in large part due to its methodology, which was participatory, educational, arts-engaged, digitally disseminated, and deeply networked in both the local community and across the province of British Columbia.

11.2 LGBT Terminology

In recent years, the acronym LGBTQ2SIA+ (Lesbian, Gay, Bisexual, Transgender, Questioning/Queer, Two-Spirit, Intersex, Asexual) has emerged in North America. Though this acronym is unwieldy and makes some people avoid discussion of LGBT issues altogether because they are anxious that they will 'use the wrong words,' it does acknowledge those not recognized in the phrase 'gay and lesbian' – the bisexual, transgender, Two-Spirit, intersex, and asexual people whose experiences and issues have been ignored. In other regions, a commonly used acronym is LGBTQ (Lesbian, Gay, Bisexual, Transgender and Queer). However, there are many in the LGBT community, particularly in the older age group, who have difficult memories of being assaulted with the call of 'queer.' In recognition of this, the Q was dropped from this acronym for the purposes of the project discussed here. There are also generational differences in the use of terminology, as many young people confidently reclaim 'queer' as an umbrella term to cover all persons identifying as gender and/or sexually non-normative. In respect for the experiences of their elders, the youth participants accepted the use of LGBT as the project's acronym.

We must also point out here at the outset that even this comprehensive umbrella acronym, and others like it, can serve to conflate the experiences of a range of individuals with very different needs, backgrounds and circumstances. Much more research is needed to understand and address these differences as they might impact LGBT elder abuse. For instances, lesbians report greater financial barriers to healthcare than gay men and are more likely to be partnered (Frederiksen-Goldsen et al. 2013). Bisexual women are at higher risk than lesbians for mental distress and poor mental health (ibid). Further, 'Ambiguity around inclusion of gender diverse people can create further barriers and anxiety about accessing support' (SafeLives 2018, p. 36) with trans women in particular concerned as to whether a women's shelter will accept her, or how she will be treated in one. Though these nuances lay beyond the scope of our project (and this chapter), they require further research.

11.3 Elder Abuse: Definitions

The definition we use in this chapter (and our project) comes from the National Initiative for Care of the Elderly (NICE),[1] who define it as the '[m]istreatment of older adults…within a trust relationship' (NICE 2015) including both actions and behaviors or lack thereof. NICE list five main forms: physical, emotional/psychological; financial/material; sexual and neglect – all of which may be experienced by both LGBT and non-LGBT victims. Westwood (2018) notes that the abuse of older LGBT people can be seen as three sub-categories, (1) elder abuse of those who are LGBT, (2) homo/transphobic abuse of LGBT persons who are also older and (3) homo/transphobic abuse of people because they are both older and LGBT.

As several commentators have noted (Carbado et al. 2013; Hill Collins and Bilge 2016; Westwood 2018, p. 3), an intersectional approach is required in order to understand 'the way(s) in which, age(ing), gender, and sexuality interact to inform the uneven experiences of older LGBT people.' Further, as Bruckert and Law (2018, p. 5) note in relation to women '[i]ntersectionality allows for nuanced analyses and sheds light on the complex interplay between social and structural factors that condition… vulnerability to…violence.' Our definition of LGBT elder abuse contains all of the above and additionally follows feminist arguments that abuse is a product of unequal power relations, not just between abuser and victim, but also in relation to how they are both situated within 'a host of interlocking, social, political, and economic systems' (Bruckert and Law 2018, p. 7).

Much of the literature we draw upon in this chapter centres on the experiences of LGBT people in North America, and our project was conducted in Canada, a country with rights and legal protections for LGBT people. Yet, as Morrissey and Waymark (2017, p. 139) note:

> …the Universal Declaration of Human Rights makes it clear that all people have the same basic rights. However, 73 countries and five entities still criminalize members of our community and several routinely kill them for their orientation.

It must be emphasized that elder abuse of LGBT people in many parts of the world includes national and institutional lack of protections.

11.4 Increased Risk Factors for LGBT Elders

As noted earlier, little is known about the prevalence of elder abuse in the LGBT population, or indeed, the needs and issues of LGBT older adults generally, who have been described as an invisible population (Brotman et al. 2003; de Vries and Blando 2004). This invisibility is caused partly by heteronormativity, which both overlooks LGBT identities and conflates them within research on heterosexual subjects (Institute of Medicine 2011) and also by a tendency towards concealment

[1] NICE is a Canadian organisation with international partnerships in nine countries.

on the part of LGBT elders (Brotman et al. 2003; Kochman 1997; National Senior Citizen's Law Center 2011). Such silence is worrying, not only because it represents an unfortunate gap in our knowledge and understandings, but also in that it is often in such silences that oppression flourishes; as feminist commentator Solnit (2017 unpaginated) has put it: 'silence is what allowed predators to rampage through the decades unchecked.' Historically, such silences have adversely affected LGBT people, for instance during the AIDS epidemic in the 1980s, a time when it was not unusual for health workers and other service providers to shun men who were sick and dying (Johnson and Stryker 1993). Indeed, it was LGBT activists in New York City who first coined the cogent LGBT slogan 'Silence = Death.'

Though the literature is largely silent on the subject of LGBT elder abuse, it does suggest that LGBT elders are more at risk of being abused than their heterosexual counterparts. For examples, LGBT individuals are less likely to be married, less likely to have children or to find their children supportive if they do have them (Fredericksen-Goldsen et al. 2013). They are more likely to live alone, as well as to feel lonely. The health impacts of exposure to discrimination are far-reaching and include increased risk of mental illness (Brotman et al. 2003; Cabaj and Stein 1996). LGBT people are more likely to be depressed, to be disabled (Frederiksen-Goldsen et al. 2013), to have experienced various forms of trauma, and to have abused drugs and alcohol (Choi and Meyer 2016). They are also at greater financial risk, because of discriminatory access to legal and social programs and lifetime disparity in earnings (Choi and Meyer 2016). All these characteristics are known risk factors for elder abuse (Pillemer et al. 2016).

11.5 LGBT Perspectives on Health Care

Historically, LGBT elders have also experienced troubled relationships with the health care system. Many have lived through extremely hostile times when their sexual orientation was criminalized or seen as a mental illness to be 'cured' by extreme therapies such as electric shock and aversion therapy. Homosexuality was removed from the Diagnostic and Statistical Manual (DSM) in 1973, but as recently as 2003, Brotman et al. (2003, p. 192) found that gay and lesbian patients of all ages still reported negative reactions from service providers, ranging from condescension, excessive curiosity and pity, through embarrassment, hostility, and outright rejection. The Williams Institute Report on Aging (Choi and Meyer 2016) cites several studies that suggest that fear of discrimination causes many older LGBT adults to avoid or delay health care and to conceal their gender and sexual identity from health providers. Such nondisclosure has been shown to be negatively associated with the quality of care LGBT seniors receive and increases isolation (Stein and Bonuck 2001).

When suspicion and fear exist around reporting even routine health problems, LGBT elders are likely to feel that reporting abuse might expose both their abusers and themselves to shame, embarrassment, and skepticism. Since they are less likely

to visit doctors, hospitals or health clinics, they are also less likely to be aware of programs or information that might help them or be confident that these will be safe or inclusive. Indeed, materials specific to LGBT elder abuse did not exist to our knowledge (in Canada at least) until they were produced in our project.

11.6 Long-Term Care Facilities

Many older LGBT people fear entering long term care (LTC) facilities, as the National Resource Center on LGBT Aging (2011, unpaginated) notes because they fear encountering hostility and being pushed back 'into the closet.' In addition, 'LGBT older adults who are cognitively or physically disabled are at a heightened risk of relocation to LTC' (Sussman et al. 2018, p. 122) where LGBT appropriate care may not be available. Sussman et al. (2018) surveyed Canadian care homes to assess the level of LGBT training and services available and concluded that whereas some were open to considering LGBT issues, the major step taken tended to comprise staff training with little or no changes to programming, for fear of negative responses from hetero-normative residents and families. Brotman et al.'s (2003) comprehensive report on the health and social service needs of LGBT seniors across Canada painted a detailed and gloomy picture of continued discrimination and ignorance in LTC facilities, and the invisibility and silence of LGBT elders in this context.

11.7 Shame, Self-Stigma, and Low Self-Esteem

LGBT elders have survived oppression, violence, and social exclusion. Their histories display tremendous strength and resilience in the face of these struggles, yet there has also been a cost. Social marginalization, stigma, and oppression have led to feelings of shame, self-stigma, and low self esteem for many LGBT elders (Yang et al. 2018; Chamberland 1996; Kaufman and Raphael 1996) – feelings that can only be compounded by the prospects of the increased dependence and physical decline that routinely accompanies aging.

Since elder abuse is about the misuse of power and the abuse of trust, then it follows that its prime targets are those who might be easily convinced that they are worthless, or 'less-than.' As Cooks-Daniel (2017, p. 543) has pointed out

> The history of social and interpersonal discrimination, violence, and trauma that LGBT elders have experienced simply adds to the ways in which they can be threatened or manipulated by abusers.

Cooks-Daniel goes on to list some LGBT-specific abuse tactics that may be employed. These include threats to 'out' the LGBT elder (with implications for access to grandchildren), suggestions that 'this is what it means to be LGBT' (for

instance in terms of abusive sexual behaviors), suggestions that 'no one will believe you' or 'they'll think you're crazy' and inappropriate access to finances. Given that same sex marriage has not always been available, assets may have been combined without sufficient protective measures. From the victims' perspective, internalized homophobia, biphobia, or transphobia may also lead them to believe that this is 'the best I can expect,' as earlier abuse make them more likely to believe that being abused is 'just the way things are.' Fear of spending the rest of their lives alone may influence their decision to remain in an abusive relationship, and social isolation may make them more dependent upon abusers. Gender issues inherent in the discourse about abuse can also be compounded in same sex relationships, as both male and female victims are perceived to be less at risk because men are seen as able to fight back, and women as unlikely to be dangerously aggressive.

11.8 LGBT Culture

Unfortunately, LGBT culture itself does not have a strong history of supporting elders, since it tends to be both youth oriented and at times ageist. In recent years, LGBT activism in Canada and the United States (US) has tended to centre upon the achievement of gay marriage. Harrison and Riggs (2006) note a significant lack of awareness and discussion of aging in LGBT public forums or media.

11.9 Raising Awareness and Addressing Elder Abuse in the LGBT Community

11.9.1 Project Description

In 2015, two community activist groups – Youth for A Change and Quirk-e – the Queer Imaging and Riting Kollective for Elders, with funding provided by the British Columbia Council to Reduce Elder Abuse, worked collaboratively on an intergenerational, community-based participatory digital arts project, *Raising Awareness and Addressing Elder Abuse in the LGBT Community* (Robson et al. 2018). The objective of the initial phase of the project was to create educational materials that would raise awareness of elder abuse in the LGBT community, in the process building knowledge of elder abuse among the participants (a topic previously unfamiliar to both the youth and the elders), build social capital, as well as art skills. The project was conducted in Greater Vancouver, British Columbia, Canada, where both groups are based. Chapter author Jen Marchbank and her wife Sylvie Traphan facilitate the youth group and chapter author Claire Robson facilitated the elder creative writer/arts activist group at the time the project was conducted (2015–2016). Chapter author Gloria Gutman led the project, and the arts component was

led by Kelsey Blair, a doctoral student in the English Department at Simon Fraser University and co-facilitator (with Robson) of Quirk-e.

In total, five posters and three videos were produced following which teams (comprising one of the three chapter authors, one youth, and one Quirk-e elder) premiered them at Town Hall meetings held in each of British Columbia's five regional health authorities. Advance invitations were sent to local LGBT organizations, health agencies, local seniors' organizations, individuals within the regional health authorities who were designated to respond to elder abuse and those focused on sexual health. Typically, we found that service providers in these latter two groups did not know or communicate with each other even though they worked for the same organization.

The goals of the Town Halls were to (1) raise awareness of elder abuse within the LGBT community; (2) raise awareness among those who provide elder abuse services of the additional risks of abuse that may accrue to LGBT older adults; and (3) familiarize both of these groups and current/potential victims with local services they might access in addressing the various types of elder abuse.

It should be noted here that both Jen Marchbank and Claire Robson are well known as LGBT activists with extensive networks in the LGBT community, while Gloria Gutman, a gerontologist, elder abuse researcher, and seniors' advocate, has strong connections with the seniors' community and agencies who provide health and social care, legal services, housing etc. targeted to them. Their extensive networks were fully exploited in promoting the Town Halls.

11.10 Project Outcomes

Three videos (available at www.sfu.ca/lgbteol) were made depicting the following scenarios: emotional/psychological and physical abuse (a lesbian couple, one of whom feels that her partner's butch appearance will out her and thus threaten her access to her grandchildren, so becomes physically abusive), financial abuse (a gay male couple where the younger partner makes unauthorized withdrawals from the older partner's bank account), and institutional neglect (a female to male trans individual being upbraided for requesting a pap smear). The five posters/fact sheets (shown as Figs. 11.1, 11.2, 11.3, 11.4, 11.5, and 11.6 below) define the five main types of abuse and list local services addressing them. All these materials were taken into six British Columbia communities (Vancouver, Surrey, Victoria, Kelowna, Nelson, and Prince George) via the Town Hall meetings (attendance = 21–57 per meeting). Two further community dialogues were held, in partnership with local community organizations, with service providers working with ethnic Chinese and ethnic South Asian seniors, the two largest ethnic minorities in the province.

At the time of writing, the project has gone far beyond the original dissemination plan. For example, the project drew the attention of the LGBT Advisory Committee of the City of Vancouver, and at their request, the posters were displayed in all 24 community centres in the city. The materials have been presented at Social Planning

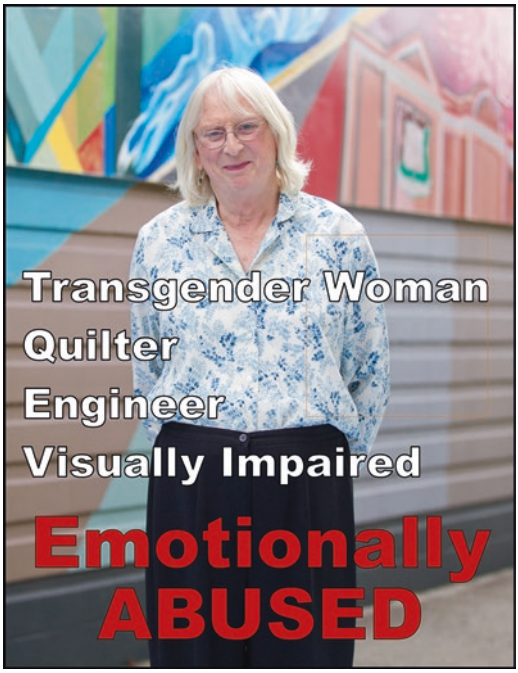

Fig. 11.1 Poster 1

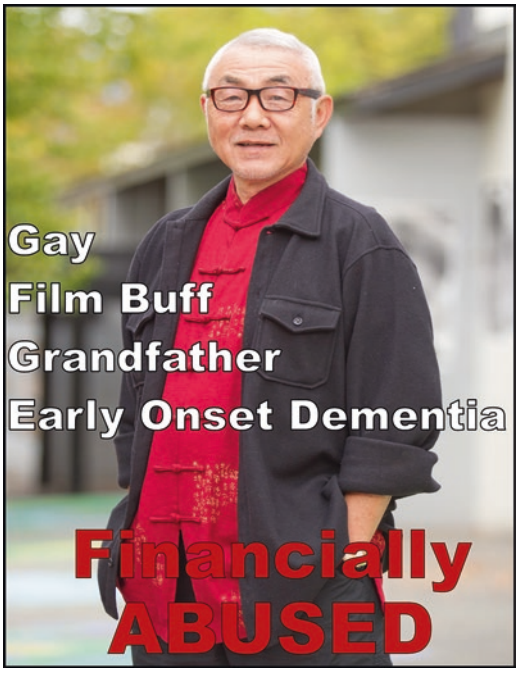

Fig. 11.2 Poster 2

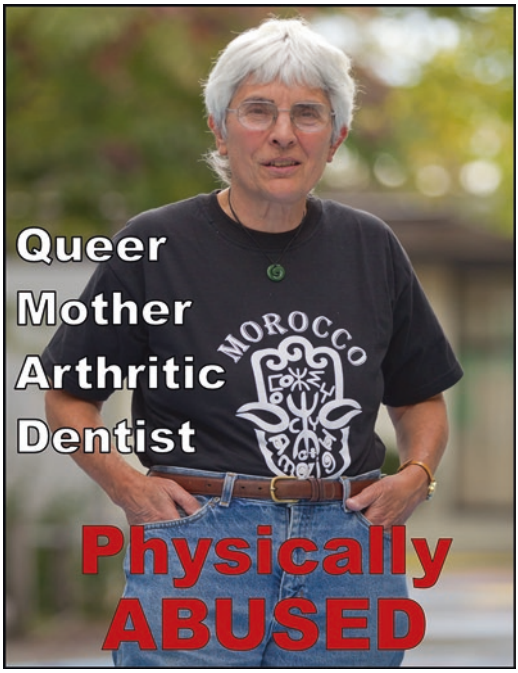

Fig. 11.3 Poster 3

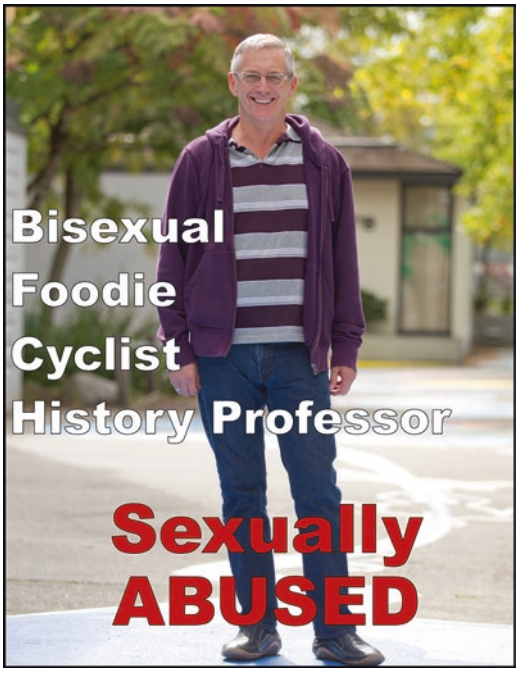

Fig. 11.4 Poster 4

Fig. 11.5 Poster 5

Committee meetings of two city councils in British Columbia. They have been integrated into the Sociology and Gender Studies curricula in two BC institutions of higher learning and into the care aide training program of a third British Columbian university. They have been used by other provinces (e.g. Nova Scotia Environment), integrated into the medical curriculum in an English university and presented at a Violence Against Women network meeting in south Scotland as well as local, national and international Gerontology, Education, and Action Research conferences. All 2500 posters have been distributed and over 1400 people have downloaded the videos.

11.11 Discussion

11.11.1 Nothing About Us Without Us

Similar to the Irish organization, Sage Advocacy (see chapter by Taylor), disability groups have used the phrase 'Nothing About Us Without Us' in order to emphasize the importance of being considered full and direct participants in the inception, discussion, development and implementation of policies that affect them. We believe that one of the most significant strengths of our project was the inclusion and direct involvement of LGBT youth and elders, not only in designing, but also in

Fig. 11.6 The reverse side of all five posters

disseminating the materials and in speaking directly to service providers, academics, and seniors' and LGBT organizations.

Older people, as a group, are often regarded as a burden, with mainstream media portraying them as 'a grey tsunami' demanding rather than providing services and thus placing a burden on taxpayers (Cruikshank 2013; Bingham 2013). As far as LGBT elders are concerned, these perceptions of frailty and helplessness are

compounded by the greater likelihood of experiencing disability, depression, mental illness, and social isolation. Though the health care system has moved beyond the outright criminalization and medicalization of LGBT individuals, narratives of helplessness and victimhood continue to dog both queer elders and queer youth (Saewyc 2007; Ryan et al. 2009). Though it is important to recognize the challenges faced by LGBT youth and elders, it is vital that service providers understand the importance of supporting their resilience, confidence, and sense of agency. Research has shown that an overemphasis on frailty by health care professionals can lead them to ignore the importance of developing resilience as a key strategy for successful aging (Resnick et al. 2011; Kuchel 2018).

It is difficult to overestimate the importance of emphasizing emotional and psychological resilience in the context of LGBT elder abuse, where continued invisibility and self-stigma are key factors. The health care providers who attended our presentations were able to put a face to the statistics and to regard our participants as experts and contributors, rather than victims and consumers. Changing the narrative contributed positively not only to the ways others viewed them, but the ways in which they viewed themselves, as they were positioned as leaders, advocates, spokespeople, and even experts. Our participants were proud of both the materials they produced and their ability to speak in public. Typically, those who attended their presentations reported that they were impressed with participants' in-depth knowledge of the issues, and their ability to answer follow-up questions or position the specifics of the discussion in broad cultural terms.

11.12 Acknowledging Intersectionality

As the youth and elders considered the design of the five posters and the three videos, they were faced with a critical artistic challenge – how to represent the complexity of LGBT elder abuse through a few simple images and brief text on the posters, and through only three scenarios on the videos. Both their discussions and their consequent choices acknowledged and forefronted the intersectionality of LGBT elders in terms of race, gender, sexual orientation, occupation, and interests. The images and texts on the posters show that abused LGBT elders are not just old and victimized, but also grandmothers, hobbyists, and exercise enthusiasts (among other identifications), and that abuse happens to people of all races and sexual orientations. Since there is considerable silence about lesbian and transgender experiences generally, the youth and elders decided to highlight these in two of the three videos. They also wanted to represent and acknowledge systemic oppression, particularly abusive situations in residential care (the subject of the third video).

11.13 Choices Around Dissemination

Much has been written about the informal networks and systems of support forged by LGBT people (Hyun-Jun et al. 2017), and we believe that it is essential to understand and utilize these in outreach. Though elder abuse materials are generally distributed in hospitals and clinics, we chose a different model, given the general mistrust of health care services by LGBT people. In addition to the screenings that occurred at Town Hall meetings, all the materials produced were and still are available digitally and free of charge, and much of our publicity was and is conducted through social media platforms familiar to LGBT and seniors' populations in British Columbia.

Another key element of our project was to involve, from the initial proposal stage, community partners (listed below), including LGBT and LGBT friendly organizations:

- QMUNITY (a nonprofit LGBTQ/2S organization for British Columbia)
- West End Seniors' Network
- Haro Park Centre (a seniors' housing and LTC facility in the heart of one of Vancouver's LGBT communities)
- Alzheimer's Society of British Columbia
- The Health Initiative for Men
- Gay and Grey Men's Group
- Quirk-e
- Youth for A Change
- Britannia Community Services Centre (located in Grandview Woodlands, another of Vancouver's LGBT communities)
- British Columbia's five health authorities (Fraser health, Interior Health, Northern Health, Vancouver Coastal Health, and Island Health)

It should also be noted that we built upon the networks of Marchbank and Robson (as noted earlier, well-known LGBT activists), and that of the third author, Gutman, who had just completed a participatory community project on end-of-life care in the LGBT community and was thus regarded as an ally (de Vries et al. 2019). We strove as far as possible to disseminate the materials in community spaces. As far as we could, we publicized the Town Hall meetings in ways that attracted not only service providers, but also local LGBT organizations, and members of the community.

11.14 Bridging Silos

Thus far in our chapter, we have not addressed the intergenerational aspect of the project, but we see this as highly important. One of the challenges facing health and other service providers is the existence of silos in and among various institutions (Seddon et al. 2013, p. 86). These silos include the separation of LGBT youth and

seniors; of academics and practitioners; and of the divisions of the health authorities that provide elder abuse services and those that are responsible for promoting sexual health. Services to seniors, especially seniors from marginalized groups such as the LGBT community and/or ethnic minority groups, must be intersectional and culturally appropriate. It cannot be assumed that services and supports that are experienced positively by hetero-normative seniors are necessarily appropriate for LGBT seniors.

Similar silos exist in the LGBT community itself, most notably across the lines of age and gender. This project demonstrated that the silos that characterize services to abused older adults, the LGBT community, and the general population of older adults can be bridged by projects that involve the local community as they reach across generations and disciplines and generate academy/community collaborations. It also served to educate younger LGBT activists about the issue of elder abuse in their community, thus constructing awareness for the community's future leaders and advocates. The ultimate aim of this project and of this chapter is to educate. We set out to educate service providers in health and social care in British Columbia, yet we believe that the project went far beyond these goals. The youth and elders developed skills in script writing, editing, acting, design, marketing, and directing. They learned about elder abuse, and educated members of the Town Hall meetings, building upon their own lived experience as LGBT persons, all whilst developing materials for service providers to incorporate into staff training activities.

11.15 Conclusion

Over 15 years ago, Brotman and her colleagues stated an urgent need to create more equitable, open, and supportive environments for LGBT elders (Brotman et al. 2003, p. 199) including the recognition of homophobia as a form of elder abuse for this community. At the time of writing, we do not believe that their call has been adequately answered. More research is needed to determine the extent of LGBT elder abuse in its various forms, by individual partners, caregivers, and family members, and by institutions. Much more action is required to address it through appropriate initiatives, such as targeted training for health and social service providers and police, and the adaptation of policies and procedures to make elder abuse services more LGBT friendly. It is essential that LGBT individuals, communities, and organizations be regarded as essential partners in processes of institutional change, and that their voices are heard, recognized and celebrated.

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Chapter 12
Gender Issues in Elder Abuse

Bridget Penhale

12.1 Introduction and Background – Key Issues

Over the last decade, the issue of elder abuse has gained importance at international and European Union (EU) levels. The World Health Organisation (WHO) and the International Network of the Prevention of Elder abuse (INPEA) have recognised the abuse of older people as a significant global problem, and this has been accepted in a more global sense. In the last three decades, there has been increasing recognition in the United Kingdom (UK) of the abuse and neglect of older adults as a social problem in need of attention, although in some other countries such recognition and resulting attention to the issue has been rather more recent. Elder abuse is a human rights violation resulting in suffering, decreased quality of life and even in some situations hastening mortality. Moreover, it is an infringement of Article 25 of the EU Charter of Fundamental Rights, which recognises and respects the rights of older people to lead lives of dignity and independence, and to participate in social and cultural life. The majority of older people are female, and more older women experience abuse than older men (even when controlling for the differences in proportion of the population). It is therefore timely to consider violence and abuse of older women as a topic in its own right. This chapter will explore a number of these issues.

Elder abuse and neglect is a complex and sensitive topic to fully and properly investigate. This situation was also found, initially, with child abuse and domestic violence against younger women. Establishing a sound theoretical base for elder mistreatment (a term used to denote elder abuse and neglect) has presented challenges, in part due to a lack of agreement about the need for a standard definition, but also because of problems in researching the topic and developing appropriate methods to do so (cf. Ogg and Munn-Giddings 1993; Penhale 1999a). However,

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despite these difficulties, a number of definitions of elder abuse have emerged and one of the definitions that is most commonly referred to is the one used by WHO and the International Network for the Prevention of Elder Abuse (INPEA), following the definition developed by the organization Action on Elder Abuse (AEA 1995). Included within most definitions and associated typologies are the following types of abuse: physical, sexual, psychological, financial (or material abuse) and neglect. To this list, additional aspects of abuse have been added such as institutional abuse, violations of rights, and social abuse; these have also been incorporated within a number of definitions and understandings of abuse. Lists of indicators of abuse have also been developed over time, although it is problematic to diagnose mistreatment (O'Keeffe et al. 2007) solely through the use of indicators. In more general terms, debate still exists about definitions, indicators of mistreatment and different aspects of abuse and neglect.

It is also clear that there is still a general lack of awareness of abuse in many countries and this can lead to difficulties in detection and identification of abuse and neglect by practitioners as well as the wider public and older people themselves. Indeed, reports of which type of abuse is most common varies between surveys, with no absolutely consistent pattern of findings and differences occurring between studies at the national level. Early American research indicated that most instances of elder abuse appear recurrent and part of a pattern, rather than a single incident (O'Malley et al. 1981).

When considering the term vulnerability and it's usage, there is a need to recognize that there are issues that relate to visibility and invisibility about what is recognized as mistreatment or not, as well as such aspects as marginalization and exclusion of individuals who may be considered vulnerable, or at risk of mistreatment and/or harm. Current understandings strongly suggest that vulnerability seems to be largely situational; this means it is not only the characteristics of the person that results in assignment of the status 'vulnerable' but instead, it is the interaction with and interplay between other situational and circumstantial factors that lead to the occurrence a vulnerable state for the individual (Penhale and Parker 2008). Vulnerability is a social construction and a social model, and, as outlined above would seem most appropriate in relation to its conceptualization within understandings of abuse. Moreover, those individuals who are often deemed to be most at risk are the people who are acknowledged to be from 'hard to reach' or 'seldom heard' groups and who may experience life on the very margins of society. This is likely to have adverse effects on individuals' health and well-being, not just in relation to physical health but also states of mental well-being and some of these impacts may be very significant. It is apparent too that some older individuals who have impairments, either due to a physical or cognitive related illness or disability - or perhaps also more complex conditions, that may combine both aspects, may also be 'hard to reach'. This is because the level of needs of such people could mean that these are not fully addressed by the service structures that exist. Such aspects as these might be particularly relevant in relation to individuals' experiences of abuse and violence, as the service structure and provision in a locality (or even nationally) may not serve these types of intersecting interests in a satisfactory or even relevant way. In addition, the

nature of public policy, provision of services and the dynamic and evolving quality of relationships between the individual and the state (perhaps in this context in particular, the welfare state) requires further exploration in relation to mistreatment, whether this is violence, abuse, neglect or exploitation (mistreatment is the term used to encompass these aspects, as suggested by O'Keeffe et al. 2007).

Additionally, a further set of issues are connected to family relations and familial matters. Throughout the last century, perhaps particularly in western and more industrialized countries, a significant number of changes occurred to family structures. Family types and patterns both altered and developed as a result of such changes; an example of this can be seen in the rise in the extent of lone parenting and increases in the number of re-constituted families following divorce and separation. Furthermore, increases in multi-generational families, some of whom share accommodation and family life have occurred in many countries, in part due to the demographic changes that have occurred globally with aging populations across most countries and the rising number of people living into late old age (Antonucci 2007). Substantial effects have also been found relating to socio-demographic factors such as gender, education, income and marital status. These and other factors have had considerable effects on the dynamics and patterns of familial relationships in the twenty-first century and also on the nature of caregiving in later life, about which we still know too little.

The issue of elder abuse was acknowledged as a social problem several decades after the recognition of child abuse and domestic violence as significant issues for society to deal with. In addition, there is a need here to acknowledge the importance of professional recognition of the issue as a problem that required attention from health and human services professionals, if not society more broadly. The situation in relation to elder abuse is similar to the situation of child abuse/protection, when in the late 1960s and early 1970s (in the UK) it was medical clinicians that first raised concerns about this form of abuse. However, concerning the area of domestic violence against younger adult women, it was activists in the second wave of the feminist movement (in the 1970s) who initially identified violence and abuse directed towards women and drew attention to the need to develop responses to the problem. This latter identification incorporated more of a 'grass-roots' and political approach by feminists to the perceived problem, and one that directed broader societal attention towards this issue. Yet in relation to elder abuse and neglect, it was not until the 1980s within a European context, that professionals began to draw attention to the issue of mistreatment and as noted, the responses were similar to those that had developed earlier with children and young people. This issue of identification is relevant, as it has had an impact on what has happened in the development of strategies concerning the prevention of abuse, protection of and provision for those who are abused, and it also informs the lack of awareness by the wider public of the issue (Penhale 2008). Additionally, it is likely that the identification and recognition of elder abuse as a social problem may also have been affected by such initial identification and orientation.

From what we know to date, elder abuse and neglect appears to be a complex and multi-factorial phenomenon. Yet, there are a number of problems in interpretations

of the evidence that exists. Several of the causal factors that have been advocated as pertinent to elder abuse seem to focus more on micro, individual level factors. As a result, potential macro, structural level factors are not wholly considered and there often seems to be an associated attribution of pathology to older people, perhaps especially individuals who have some form of disability, of whatever type. One instance of this can be seen when an older person who is dependent on others for needs relating to care and support is perceived as a source of stress and as a result is viewed as responsible (at least to some extent) for abuse that arises within such situations. Perceptions of pathology such as these may suggest confirmation of existing societal views and opinions of older people as dependent and powerless, which is not helpful. In spite of sustained attempts to disseminate the social model of disability across societies, the example provided in relation to older people is very similar to existing and still relatively prevalent societal perceptions of disabled people as both dependent and helpless and consequently not able to either care for themselves or live independently.

In general, older women are disproportionately affected by disability, poverty and violence. Through the course of a lifetime, gender-based differences in employment, healthcare and education negatively influence the physical and mental wellbeing of women, with a cumulative effect in later life (World Health Organization 2015). Therefore, people who are both older and disabled might be more likely to be considered as helpless and dependent and as a result to experience an increase in vulnerability, due to this intersectionality between age and disability (Crockett et al. 2018). Such situational vulnerability, discussed above, which is made more complex by intersectional issues like this, also includes exposure to mistreatment so that older disabled individuals (and in particular women) are more likely to experience violence in their daily lives. On the other hand, this type of positioning of older and disabled people as dependent and powerless also fails to take account of the potential role of a number of other aspects, one example being the potential of neighborhood and community to provide support (Buffel et al. 2009) to act as protective factors against the development of situations that are abusive in nature.

12.2 Violence Against Women: Including Gender in Elder Abuse

Since the 1970s, we have seen the development of an acknowledgement that violence against women is a human rights and public health issue, with significant and enduring impacts on women's life and health. In recent years, an increasing number of studies have started to explore women's experience of violence at different ages – including the extent to which older women experience partner abuse.

Around 500,000 older people are believed to be abused at any one time in the UK, with most victims of elder abuse being older women with a chronic illness or disability, according to statistics provided by the government information service. The

recent Women's Aid and *Counting Dead Women project* annual Femicide Report shows that of those women killed, most of the women aged over 60 years were killed by a male family member, either a spouse or a son/grandson (Long et al. 2018).

Older women experiencing domestic and/or sexual violence may be afraid to seek help or may not know how to access support and they are less likely to report crimes or to make use of any services that might be available (Beaulaurier et al. 2008; Blood 2004; Safe Lives 2016).

Older women face particular obstacles to disclosure and help-seeking, which have not been adequately acknowledged and are not sufficiently understood or provided for. Against the backdrop of the global ageing population, it is fundamental that health and social care professionals are able to both identify gender-based violence and abuse and understand the particular experiences, needs and rights of older women. Gender based violence and abuse amongst older women can be overlooked by health and social care providers, with their (understandable) perspectives on and orientation towards health, care and welfare. It is apparent that when women become 'older' their gender seems to be forgotten or becomes hidden, or invisible. This means that older women's experiences of gender-based violence may often not be either recognized or responded to in an appropriate and timely way. Thus, it is likely that professional practice that is both age-sensitive and gender-responsive is needed (Crockett et al. 2018).

Whilst violence against older women is often only considered in the context of care and dependency (Bows 2019), several reviews have shown that violence against older women is mainly perpetrated by intimate partners (for example, see Penhale 2003). Although a number of studies suggest that the prevalence of intimate partner violence (IPV) is lower among older women when compared to rates of IPV towards younger women (Burazeri et al. 2005; Helweg-Larsen et al. 2011), we need to be cautious about comparisons of this kind, as these studies are mainly small scale and with differential coverage in terms of research designs, measurements of violence and age categories. Furthermore, apart from the 1992 National Violence against Women Survey (Greenfeld et al. 1998), and National Crime Victimization surveys in the United States (US) held in 1993 and 1999 (Rennison 2001), few studies consist of data that is nationally representative. Yon and colleagues undertook a systematic review and meta-analysis of self-reported elder abuse by older women living in the community and found that despite significant variations in prevalence, and lack of robust evidence, particularly in low and middle-income countries, about 1 in 6 women experience abuse across the world (Yon et al. 2019). In addition, intimate partner violence towards older women is often viewed in the context of their perceived greater vulnerability and dependency on their partner (but see above for comments on vulnerability). However, this has been rebutted by several small-scale studies that show quite similar factors associated with intimate partner violence amongst older and younger women (cf. Phillips 2000).

Numerous studies have shown that intimate partner violence has significant adverse physical and psychological health outcomes, especially among older women (Fisher and Regan 2006; Fisher et al. 2011; Mouton 2003), regardless of whether such violence is a continuation of violence that has occurred throughout the

history of the relationship, or whether it has commenced 'de novo' in older age. Addressing intimate partner violence among older women is therefore not only important in itself, but there are also some evident implications for their health, well-being and physical functioning (Stockl and Penhale 2015). In order to develop appropriate and effective interventions relating to older women who experience intimate partner violence, more needs to be known about its prevalence and the factors associated with increased risk.

In Europe, several representative studies have investigated the prevalence of intimate partner violence and the factors associated with it at national levels (Hagemann-White 2001). Unfortunately, only a few of these surveys included women above the age of 50 years (Burazeri et al. 2005; Helweg-Larsen et al. 2011; Papadakaki et al. 2009; Zorrilla et al. 2010). There is large variation between these studies relating to the age categories used for women above reproductive age and sometimes these are not provided at all. Although the overall findings of these studies was that the lifetime prevalence of intimate partner violence reduced with increasing age, none of the studies specifically investigated what results in older women being at increased risk of intimate partner violence, with an inherent implicit assumption that factors associated with this would be similar (if not exactly the same) across different age cohorts. In addition, two more recent prevalence studies of elder abuse in Europe did not fully consider intimate partner violence in later life, but rather focused on the wider context of elder abuse and abuse against older women (Soares et al. 2010; Luoma et al. 2011). Another European study on intimate partner violence against older women did not explore either prevalence or factors associated with it (Nagele et al. 2011) but rather considered help-seeking and perceptions of responses. For these reasons, a key remaining gap is representative, population-based data to enable comparisons of prevalence rates and risk factors associated with intimate partner violence across generations, or with a specific focus on mid- and later life (Rennison and Rand 2003).

Throughout the literature on elder abuse and the evidence base from research that has developed in the past two decades, it is generally understood that males are more likely to abuse than women and that women are more likely to be abused than men within situations of elder abuse (Brossoie and Roberto 2015). This may lead to some suggestion that labels men as abusers/perpetrators and women as abused/victims. When that consideration is simply on a numerical basis, this appears to be a reasonably clear finding, but there is a need for abuse to be understood from a much broader perspective. Such a perception necessitates an understanding of the societal context(s) of abuse. This would also require, for instance, an appreciation of the possibility that some women act abusively, and that some men experience abuse (Soares et al. 2010; Teaster et al. 2007). Furthermore, it is possible that the proportion of older men who experience and report some form of elder abuse is perhaps higher than the proportion of younger adult men who report abuse in relation to what might be considered to be situations of domestic violence (Soares et al. 2010).

Whilst it is apparent that both older men and women experience abuse, the majority of victims of elder abuse are female, even when this is corrected for by the fact that there are more older women in the population (Brossoie and Roberto 2015).

Further, while there is still uncertainty regarding the rates of elder abuse either as an overall figure or with regard to the various sub-types, due to a lack of international comparative prevalence data, it can be stated with some certainty that abuse within the domestic setting occurs across all ethnic and socio-economic groups and in both urban and rural areas (Acierno et al. 2010). However, it is generally recognized that in relation to sexual abuse of elders, the majority of those who experience such abuse are women (Bows 2018; Teaster and Roberto 2004). Through the life-course, women are more likely than men to experience violence from an intimate partner, to be a victim of sexual assault, to live in poverty, develop a disability or to have reduced access to education and healthcare. As they age, the enduring and cumulative effects of these differences increase (Crockett et al. 2018; Mears 2015). Older women of color, which includes individuals from immigrant communities, older women with disabilities, and older lesbian, bisexual and trans-women, may in addition face greater, exceptional difficulties (Mears 2015). A composite of barriers due to attitudes, policies or resources may lead to exacerbation of situational vulnerability for older women, in an intersectional and stigmatizing way (Choi et al. 2017).

Those who are involved in mistreatment may be male, female; partners, adult children or other relatives. As found with other forms of familial violence, the majority of abusers are men. If the probability of abuse is corrected for by the amount of time that the perpetrator spends with the victim, men are much more likely to be involved in abusive acts, particularly those which are physically violent (Finkelhor 1983). Traditionally, elder abuse that happens in domestic settings has been seen as a problem occurring between a female abuser, often a caregiver (perhaps a daughter), and older parents. A number of early studies of elder abuse indicated that abusers were more likely to be female, usually relatives (Eastman 1984). Nevertheless, following further analyses of such data, including attention given to a distinction between physical abuse and neglectful acts (and/or omissions), it has been established that men are more likely to be involved in physical violence and women in neglectful acts (Miller and Dodder 1989; Sengstock 1991). Since categories of neglect were very high in the studies that were reviewed this largely explained why it had appeared that the majority of abusers were women.

Research concerning the characteristics of abusers and abused has indicated rather contradictory results regarding gender. Adult Protective Service figures reveal most victims are female (68%) (Tatara 1993) and in the UK prevalence study, older women reported mistreatment at more than double the rate of older men (3.8% vs 1.1%) (O'Keeffe et al. 2007). The prevalence study undertaken in Ireland using a comparable methodology established that older women (2.4%) were more likely to report experiences of mistreatment in the previous year than older men (1.9%) (Naughton et al. 2010). In the early prevalence survey, which used telephone calls conducted from Boston in the US, the majority of victims were male (52%) (Pillemer and Finkelhor 1988), whilst 65% of respondents to the calls and who undertook the survey were female. The victimization rate for men at 5.1% was double that for women (2.5%) and yet the older population was disproportionately female. It must be taken into account, however, that women tend to sustain more serious abuse and injuries than men (Swan et al. 2008). This might mean that older women are more

likely to need treatment for their injuries and other necessary forms of support and that they may also be more likely to come to the attention of authorities and service organizations.

It is possible, for instance, that women are more likely to report acts of mistreatment than men or possibly, even, to seek assistance, although evidence about this is limited. Also, as already stated, men are more likely to be physically violent and to commit more serious violence than women. Thus, if much elder abuse is between partners in later life, and the principal form of abuse for male abusers is physical violence towards women, which may perhaps lead to a need for treatment, then it could appear that more women are abused than men. Abusive behavior by women, that is likely to be psychological or passively neglectful in type, may not result in the need for any treatment for the male victim, or even any external reporting and so it is possible that this might not come to the attention of professionals or authorities. There may also be factors related to age cohorts involved here. In the UK prevalence study (O'Keeffe et al. 2007), more older men in the oldest cohort (over 85 years) reported abuse than older women of comparable ages (who predominantly reported neglect). The most frequent report of abuse by older men of this age grouping was of financial abuse. However, it is possible that the older male respondents perceived it as easier, or less stigmatizing to report financial abuse rather than, for example, physical violence. As is found with younger women, sexual abuse in later life appears to be highly gendered: those who are victims are female; those who abuse are male (Bows 2019).

One of the acknowledged and established risk factors for elder abuse concerns living with others and as men are more likely to live with someone else in old age, this may well increase the risk to older men and possibly make abuse of older men more likely. The early, seminal work of Kosberg (1998) and Pritchard (2001) in considering the needs of older men who experience abuse is important to note here. There is also some consistency with research into the characteristics of abusers: someone who has lived with victim for a long time. The person involved as a perpetrator is most often a relative, usually adult children, spouses, grandchildren, siblings then other relatives. The first prevalence study, undertaken in the US by Pillemer and Finkelhor (1988) found that abuse was mainly between partners in later life and that abuse by non-family members was comparatively rare, a finding that has been repeated in later prevalence studies (for example O'Keeffe et al. 2007; Luoma et al. 2011). More recent studies have established that for certain forms of mistreatment, such as financial abuse, perpetration by other family members (who were not partners) may be more likely (O'Keeffe et al. 2007; Naughton et al. 2010).

Kosberg (1998) suggested that in a number of situations, the motivation of revenge or 'pay back' for previous abuses of power within relationships may operate. In this type of situation, a woman or children who experienced abuse from a man at an earlier point in their family's history may see the opportunity to act abusively as a form of revenge on the man in later life, in particular if the man is in need of care and support. Research in Sweden by Grafstrom et al. (1992) which examined caregivers' experiences found some evidence for this type of dynamic taking place (see also Volmert and Lindland 2016). However, Jack (1994) suggests

that female-to-female and female to male abuse need to be situated within the context of exchange relationships within a dysfunctional and discriminatory society.

The potential effects of gender within abuse are influenced by a number of factors. These include the type of abuse which occurs; the fact that there are more older women within the population and that more women than men live alone in later life (Arber and Ginn 1995), yet there is a higher risk of abuse occurring when people live together. The different types of abuse that mistreatment consists of also do not help to clarify the role of gender within such situations.

There are a further set of critical factors that need to be recognized when mistreatment of older people and the potential role of gender is considered. The societal, social, relational and cultural contexts concerning situations that happen need to be carefully considered (Penhale and Parker 2008). As the phenomena of abuse and mistreatment are socially constructed, it is essential that the meanings and understandings ascribed to situations by individuals are properly taken into account (Biggs et al. 1995). The structural context is the background in which mistreatment is accepted and at the same time viewed as behavior that is permitted in society. To this extent, ageism would seem to be a 'master category' in the power relationships that affect older people (Penhale et al. 2000).

However, other intersectional interests such as gender and disability are clearly of relevance and need to be properly considered in relation to this. In addition, we also need to extend our knowledge and understanding of issues relating to both gender and power relations (Brandl 2000; Brandl et al. 2003; Cooper and Crockett 2015; Crockett et al. 2015; Whittaker 1995) and the relative roles of these aspects in the development and maintenance of both abuse and abusive situations. The concurrence and inter-relations between age, disability and violence are also of increasing interest and concern and to these further intersections of gender and race might also be usefully added. There is a clear need for intersectional approaches that incorporate the nexus of age, disability, gender and violence (Crockett et al. 2018). From a life-course perspective, it is clear that so far less attention has been paid to the latter stages of life, and this needs to be rectified.

Further, in the broad spectrum that comprises elder mistreatment, it is apparent that there is a range of actions and behaviors (including some lack of actions and some failures to act) that should be considered as indicative of abuse. When considering the range of mistreatment that exists, it is also clear that it is not just familial and interpersonal relationships and violence that are relevant, but other aspects like institutional forms of mistreatment are of importance and must to be taken into account of (Stanley et al. 1999). We should also acknowledge that this ought to be of particular disquiet when we consider that those individuals who are most likely to be at risk of such harms are older disabled women – and they are also more likely to be admitted to institutional care.

As stated, elder mistreatment should not be seen merely in the context of families and interpersonal relationships. The fluid nature of power relations and the continuing prevalence of patriarchal assumptions are also linked to abuse within the context of health and social care. Social and health care agencies accountable for 'protective responsibility' (Stevenson and Parsloe 1993) may inadvertently or even overtly mis-

treat individuals to whom they owe a duty of care (Penhale and Parker 2008). In an analysis of welfare and formal care provision, Jack (1994) suggested that dependence, power and control were encompassed within care relationships and that mutual (although unequal) dependency, powerlessness and violation frequently results in and maintains abuse by formal carers.

In an early attempt to consider aspects of gender more appropriately, Whittaker suggested that looking at differing types of abuse as being examples of 'family violence' or 'carer stress' results in an obfuscation of the effects of gender (Whittaker 1995). It is therefore proposed that the general concept of 'elder abuse' should be more closely examined and that more emphasis should be given to the nature of power within relationships, which would necessitate further consideration of gender. This would also require recognition of the oppression of women as being socially, economically and politically controlled by men, following feminist analyses. Aspects of this control frequently occur in male violence against women; one element of this is abuse between partners in a relationship (Whalen 1996). Therefore, the degree to which such an analysis is appropriate in relation to elder abuse and perhaps more particularly the abuse of older women still needs additional exploration.

In terms of responses to abusive situations and potential service provision, a link might also be usefully made when considering the use of refuges or "safe houses" to offer protection for older women who have experienced abuse. The major provider of "Battered Women's Refuges" (as they were originally named) in the UK, Women's Aid, have maintained a stance that they do not discriminate on grounds of age and that their services are equally available for older women who have been subject to abuse. However, for several different but inter-related reasons, it may be unlikely that an older woman would choose to use such a resource. Nevertheless, the development of safe houses specifically for older women who have been victims of abuse could be very useful, as this would be based on a very different set of assumptions than the seemingly predominant model of institutional care as appropriate for elders who have been abused (Cabness 1989; Vinton 1992). Progress in this area has been reported in recent years and looks set to continue, with at least one refuge available for women older than 50 years currently available in the UK.

12.3 Future Directions

One key area that requires further research is to try and determine the nature of both commonalities and differences between domestic violence and the abuse of older women. This would include a need to explore issues of dependency and vulnerability that women may experience throughout the life-course and how these may alter over time. We need to discover more about why certain people, such as women, people with dementia and other mental and physical health difficulties appear to be at more risk of abuse (Penhale 1999b). Specifically, identification of those factors

that seem to render or increase individuals' vulnerability would be helpful in the search to resolve and even prevent abusive situations.

Some useful work has been undertaken concerning the use of screening tools for abuse of older and younger women (Ejaz et al. 2001). Such work could perhaps be extended to other related areas and different assessment formats in relation to responding to mistreatment. Further to this, following consideration of the preliminary stages of screening and assessment, it would be useful to consider the extent to which approaches to intervention in abusive situations experienced by women at different stages of the life-course are shared or distinctive and the relative usefulness of such approaches. Action-research concerning the use of shelters, is an example of such an approach that could be taken.

It would also seem appropriate to further examine the links between mistreatment that takes place in domestic settings with that which happens in institutional environments. More investigation of the settings in which abuse may occur is likely to prove useful. Research that explores the nature and effects of power relations both within relationships and different situations might find some interesting areas of correspondence between domestic and institutional settings. This would add to knowledge and understanding of some of the key dynamics of abuse.

It also seems clear that not enough is known about which strategies of intervention work best and are most effective in which situation to be able to state unequivocally that a particular intervention is best for a specific type of mistreatment. This is especially likely to be so in relation to under-researched areas like the abuse of older disabled women. Evidently, work in this area needs to include the perspectives of individuals on their situations and incorporating their views about the impacts of mistreatment. These aspects will likely require more attention in future. Undoubtedly the intersections between age, disability, gender and abuse are fundamental here; establishing which perspective(s), preventive strategies and interventions will be most helpful in meeting the requirements and circumstances of those whose needs fall within these intersections is essential.

Finally, the societal and structural concomitants of abuse, such as the poverty and oppression that many older people experience, would seem to be worth further research. More in-depth investigation of aspects such as gender, power, disability and ethnicity in situations of mistreatment would likely assist with this (Crockett et al. 2018). This would be particularly pertinent as a means to try and establish the extent to which such aspects both perpetuate abusive situations and exacerbate them or even militate against their resolution. In addition to this, exploration of the links between the oppression of older people (in particular older women) and that of younger women or disabled people would also be of value in a wider consideration of different aspects of interpersonal violence. This would include those areas that are in common and shared and those that are distinctive to particular forms of violence and abuse. Further understanding of and knowledge about different types of abuse and violence will clearly be useful in the efforts to prevent and resolve such mistreatment in future.

12.4 Concluding Comments

In order to further develop the field, a number of different approaches need to be used. It is apparent that there is a need to improve awareness and recognition of mistreatment, across the general public, professionals and perhaps most importantly, the older population. Work needs to happen to develop knowledge and understanding about abuse and neglect, and the inter-related aspects of causal factors and consequences and the interplay of gender and power relations within such situations. Development of theoretical and conceptual frameworks and foundations are also of central importance here (Ploeg et al. 2009; Podnieks et al. 2010) and these need to include gender perspectives, as appropriate. Social perspectives on abuse must also be fully incorporated in such frameworks. Above all, it is imperative that the voices of older people, particularly those who have experienced abusive and neglectful situations are central to such developments and that these include those who are most marginalized and excluded, many of whom are women.

Several of these approaches will need thorough research and development to happen. There is a need for intervention studies to be undertaken in order to ascertain which techniques of intervention work best and in which circumstances. This could include the development of model projects for different interventions, with appropriate and rigorous evaluation of the different projects in order to determine relevant areas for future development. Research on effectiveness and impact, not just of interventions but also the impact of abuse and neglect, together with the effect(s) of processes and interventions on individuals who have experienced or are at risk of abuse and harm also needs to happen. Further work on the differing models of service provision (for example different types of specialist teams) should occur, but as it is not clear yet which model might work best, and in which situation or for which type of abuse; in-depth research and evaluation of such models would be advantageous and would be likely to be useful for developmental reasons.

Likewise, it is also necessary to ensure that there is sufficient focus on individualized and personalized approaches for those people who experience mistreatment and harm; as far as possible these types of approaches should be tailored to the needs of particular individuals. Key and central issues here relate to autonomy, choice, empowerment, and, independence, with additional essential elements relating to individuals' capacity and consent. Independence, self-determination and service user-control are not necessarily in opposition to matters relating to individual safety and protection. Indeed, most safety planning for older people aims to support and empower individuals to keep themselves safe and to change their own situations (if they are willing and able to do so). If we are to achieve the aim of assisting all older people to live their final years free from abuse, neglect and exploitation there must be more research, development and international collaboration to further counteract the differing and pervasive forms of mistreatment that exist. Attention to issues relating to gender equality and the needs of older women will assist in this endeavor.

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Chapter 13
Danger in Safe Spaces? Resident-to-Resident Aggression in Institutional Care

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13.1 Introduction

In recent years, violence and abuse in caregiving contexts (both in institutional and community settings) have increasingly become topics of research and discussion (see, for example, Dong 2015, Lachs and Pillemer 2015, Yon et al. 2018). The main focus of research is on the behaviour of caregivers towards care recipients, usually addressed under terms such as 'elder abuse and neglect' or 'mistreatment of older adults'. Research also touches upon care recipients' violence and aggression towards professional and lay caregivers, often referred to as a type of 'challenging behaviour' (e.g. Hazelhof et al. 2016; Pieper et al. 2016). For the field of institutional care, Fig. 13.1 displays basic categories of interpersonal violent or aggressive behaviour within and between the groups of nursing staff and residents. As a type of workplace violence, physical and verbal aggression may also occur between professional caregivers (e.g. Berry et al. 2016). Only recently have phenomena of aggression and violence among residents started to gain attention. Based mainly on current research from Germany, the chapter looks at these phenomena.

Rosen et al. (2008:1398) use the term 'resident-to-resident aggression' and define it as

> …negative and aggressive physical, sexual or verbal interactions between long-term care residents that in a community setting would likely be construed as unwelcome and have high potential to cause physical or psychological distress in the recipient.

The focus of this definition is upon an interaction's effects or consequences, while at the same time emphasizing the importance of the context of 'institutional care'

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		Person / group displaying aggressive / violent behaviour	
		Nursing staff	*Residents*
Person / group affected by aggressive / violent behaviour	*Nursing staff*	(A) bullying / lateral workplace violence	(B) care recipients' 'challenging behaviour' towards staff
	Residents	(C) elder abuse and neglect	(D) resident -to- resident aggression

Fig. 13.1 A 2×2 scheme of aggressive interactions between nursing staff and residents in institutional care

for the perception and evaluation of (inter-) actions. Both the definition provided by Rosen et al. (2008) and their abbreviation RRA for 'resident-to-resident aggression' will be applied throughout this chapter.

RRA research can be considered a challenging task. Official statistics can hardly be expected to provide a valid picture of aggressive incidents among nursing home residents. Older care recipients, especially when affected by dementia and related disorders, represent a 'hard-to-reach population' (Johnston and Sabin 2010) with limitations regarding understanding of questions, reliability of answers, and capacity to provide informed consent (see Quinn 2010). These very same limitations can be assumed to be linked to both the probability of becoming a victim of RRA and an RRA perpetrator. RRA research requires inclusion of multiple perspectives, including (as far as possible) residents' voices.

A recent review (Goergen 2017) provides an overview on international RRA research. Some outlines of the current state of knowledge are summarized below.

- RRA is not limited to physical violence but includes sexual assault, verbal aggression, humiliating behaviour, and forms of social exclusion. A collection of cases handled by criminal courts points at the fact that RRA may lead to fatal outcomes (Goergen 2017, see also Caspi 2018).
- While prevalence and incidence of RRA are hard to measure, several studies – using different methodological approaches and different reference periods – arrive at victimisation prevalence rates around 20% (of nursing home residents). This may be taken as an indicator that RRA goes far beyond single isolated cases. Existing research indicates that aggressive and violent behaviour is not spread evenly over the resident population; rather – just as in violence in community settings – a small number of residents appear to be committing a large proportion of all (severe) offences.

- Just as other types of violence (e.g. intimate partner violence, child abuse), RRA affects physical and mental health and well-being and may have an impact on institutional climate and quality of life in nursing homes. At the same time, consequences of victimization are highly specific, depending not only on features of the offence but also on victim characteristics (health, victimization history) and on features of the social context, such as availability and quality of social support.
- RRA events are determined by multiple factors, including victim and offender characteristics, situational cues, and organizational attributes. Connections between physical health and functional capacity on the one hand and both victimisation and offending risks on the other, appear to be complex. Dementia may be a background factor of aggressive behaviour but needs to be seen in a comprehensive perspective and in its interaction with variables such as pain and depression. Situational features such as noise, crowding, and invasion of personal space may be relevant. Currently, little is known about the influence of organisational characteristics such as unit size, staffing, institutional climate and policies.
- For nursing staff, encountering aggressive behaviour by residents has some degree of ordinariness; their coping strategies mainly develop against this background of everyday professional experience. They include measures aimed at eliminating opportunities and triggers as well as de-escalation and mediation. Nurses emphasise the importance of empathy towards residents and the motives behind their behaviour for RRA prevention.
- Beyond the use of physical or pharmacological restraints, the development of specific approaches addressing RRA is still in its beginnings. Approaches include staff training, such as the SEARCH strategy (for Support, Evaluate, Act, Report, Care plan, Help to avoid; see Ellis et al. 2014, Teresi et al. 2013), and changes in the spatial environment.

13.2 Research on Resident-to-Resident Aggression in German Nursing Homes

The remaining section of the chapter will provide data from a recent German study on ‘Resident-to-Resident Aggression in Long-Term Care’. The study received funding from the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and was conducted in close collaboration between German Police University (Muenster) and the Centre for Quality in Care (Berlin).

Before the study and selected findings are presented, some basic data on caregiving and care dependency in Germany will be provided. At the end of the year 2015, 2.86 million people drew benefits from German Long-Term Care Insurance, 27% of them living in institutions, and 73% in community settings. All over Germany, 13,600 nursing homes and day-care facilities with 929,000 beds and a staff of approximately 730,000 were available. Eighty four percent of the workforce were female; about half of the employees were skilled staff with specific training, usually lasting several years. Thirty five and a half percent of the beds were located in

double and multi-occupancy rooms. Forty two percent of the homes were in private ownership, while 53% were run by charities. Among the residents, 51% were in the 85 years+ range. The proportion of residents with 'severely impaired everyday competence' (a term formerly used in German Long-term Care Insurance Law) in nursing homes amounted to 71% and was significantly higher than among care recipients in community settings (31%; see Statistisches Bundesamt 2017). German nursing homes are regulated under governing legislation. Compliance with the federal and state legislatures are reviewed regularly for adherence to standards of building codes, care plans, nutrition and dietary services, medical services, nursing and personal care, and recreational programs (Schmitz and Schnabel 2006).

13.3 Study Aims

The main aim of the study was to provide quantitative and qualitative data on RRA in institutional eldercare in Germany. This refers to the phenomenology of violent and aggressive behaviour (including characteristics of persons involved in aggressive episodes, and situational and context characteristics), its (perceived) prevalence, and consequences of RRA incidents, triggers, risk factors and protective factors. The second main aim was to analyse the significance of RRA incidents for everyday nursing work and other groups of practitioners, the ways in which staff and institutions handle such incidents and cope with them.

13.4 Research Design

The study follows a mixed-methods approach. Its first component is a quantitative paper-and-pencil survey (35 questions on 12 pages) among staff in long-term care institutions for the elderly. This survey covers experiences of RRA and respondents' experiences with aggression of residents directed at staff, known as challenging behaviour (Hazelhof et al. 2016; Pieper et al. 2016) or 'resident-to-staff-aggression' (RSA) (Lachs et al. 2013), as well as institutional handling of cases, individual coping behaviour and education and training needs.

Questions on RSA and RRA as well as on location and timing of incidents have been developed on the basis of measures used by Lachs et al. (2016). RSA was measured with 13 questions and RRA with 15 questions (each also had an open answer field for 'other behaviour', cf. Answer categories were 'no', 'yes, once', and 'yes, multiple times' and referred both to the time since the respondent joined the current institution and to the last 4 weeks. Consequently, prevalence could be measured as time-in-institution-prevalence (tip[1]) and as 4-weeks prevalence (4wp) (Table 13.1).

[1] Tip-prevalence stems from the question (e.g.): 'Have you, since you have been working in this institution, ever experienced that a resident has screamed at you?'

Table 13.1 Measures for RSA and RRA experienced responses observed by nursing home staff

Type of behaviour	Behavioural categories
Verbal aggression **5 questions**	Screaming at someone; insulting someone.; bossing someone around; intimidating or verbally threatening someone; threatening with fist, cane, other object
Physical aggression **6 questions**	Hitting or kicking someone; roughly grabbing or yanking someone; throwing things at someone, pushing or shoving so; deliberately spitting, scratching or pinching someone; ramming someone with a walker or wheelchair
Sexual acts/ harassment/assault **3 questions**	Using inappropriate sexualised language towards someone; touching someone in a sexually harassing manner; intimately touching oneself in front of someone *(last item RRA only)*
Other behaviour	Walking into another residents' room and touching, damaging or taking his/her belongings *(RRA only)*

Furthermore, an additional institutional survey with 14 questions on four pages was sent to the nursing home management in the participating facilities. The questionnaire mainly focussed on socio-demographic data of residents, institutional ownership, size of the nursing home, care levels (indicating degree of care dependency and support needs), and number of court-ordered legal guardianships among the residents.

The staff sample was composed of 1326 persons who are employed or work in care and assistance of residents, from 72 long-term care facilities in the federal state of North Rhine-Westphalia. The majority of the long-term care facilities were run by charities (n = 49), four facilities were run by municipalities (or other public bodies) and 19 were private enterprises. The state of North Rhine-Westphalia has a population of nearly 18 million. Several large cities (above 100,000 inhabitants), smaller cities (20,000–100,000 inhabitants) and villages (below 20,000 inhabitants.) have been selected as a proportionate stratified random sample of municipalities. Within each municipality, institutions were selected via simple random sampling. The response rate of participants was 31.8%. The survey was conducted between June 2017 and March 2018.

The second methodological approach to RRA was an in-depth interview study in four nursing homes, addressing residents as well as staff, probing into experiences with violence and aggression in residential care. The study was conducted using separate semi-structured interview guidelines for staff, management and residents, as well as templates recording social data, and interview postscripts. The staff interviews centred on verbal, physical and sexual resident-to-resident aggression the interviewee had witnessed, ways of dealing with violent episodes, and education and training in this respect. In addition, nursing and other staff were asked about their personal experiences with aggressive acts perpetrated by residents, management were asked about strategies for preventing resident–to-resident aggression in the institution. The interview guideline for residents focussed on life in the institution, in particular on conflicts or violent episodes the interviewee had experienced or observed. All interviews were recorded and transcribed verbatim for analysis.

During the study in 2017 and 2018, 80 participants were interviewed, of which 56 were members of staff (including management) and 24 were residents of four long-term care facilities in North Rhine-Westphalia. From all municipalities in the Muenster administrative district (Regierungsbezirk Muenster), two large cities, one smaller city and one village were selected as study areas by way of random sampling. Within each of the four municipalities, one long-term care facility was selected. This was done sequentially and at random, but taking into account variation in facility size and ownership. In each of the four facilities, 20 participants were interviewed, of which 14 were staff/management and six were residents. Staff members and residents were randomly sampled by way of anonymized staff lists or by lists of room numbers, both provided by the facility's management. Members of staff that did not work in nursing were to be included in the list if they spent at least half their working time in direct contact with the residents. Residents who were ultimately not suitable for interview were only excluded after the sampling process and only after careful consideration and with a documentation of reasons.

13.5 Findings

13.5.1 Findings from the Survey

Sample 85.3% of the 1317 respondents were female, which closely matches the overall distribution for nursing home staff in Germany of 87% in 2015 (Statistisches Bundesamt 2017).

Most of the participants worked as qualified nurses (n = 523) or care assistants (n = 436), but staff from numerous other occupational backgrounds were included in the survey, such as social workers, therapists, untrained staff and more. Since the survey addressed all persons affiliated with care and assistance of residents and thus included some honorary helpers (n = 19), the age range of respondents varied from 17 up to 85 years (M = 44.3 years). Length of employment/activity in the current institution (n = 1310) was quite high (10 years or more = 33.3%; 5-10 years = 21.9; 1−5 years = 32.8%; <1 years =12%).

The large majority of participants (88.2%) stated that German was their mother tongue (including bilinguals). This characteristic served as a proxy variable for migration background. A German study conducted in 2015 estimated the percentage of nursing staff with migration background to be in the 15–23% range (Kohls 2015); thus, there may be a small participation bias in our survey (that was conducted in German language only).

Experiences with RSA and RRA When asked about their own experiences with RSA, reports of participants show a high time-in-institution-prevalence (tip), as well as four-weeks-prevalence (4wp) for verbal and physical victimization. Sexual acts, (verbal) sexual harassment or sexual assault through residents were reported less frequently, but still seem to occur on a regular basis (Table 13.2).

Table 13.2 Overview on time-in-institution and four-weeks-prevalence of RSA and RRA behaviour

Experienced/observed behaviour	RSA: tip % (1313 ≤ N ≤ 1317) 4wp % (1238 ≤ N ≤ 1283)	RRA: tip % (1316 ≤ N ≤ 1320) 4wp % (1265 ≤ N ≤ 1297)
Verbal aggression	87.3	88.5
	63.4	69.3
Physical aggression	70.0	60.1
	37.6	33.3
Sexual harassment/assault	42.5	27.4
	14.3	9.9

Observation of resident-to-resident-aggression is similarly widespread (Table 13.2) and multiple forms of violence have been witnessed by participants. Also, 70% of participants (tip, n = 1310; 4wp: 48.7%, n = 1249) observed/experienced that a resident went into another resident's room and touched, damaged or took his/her belongings. Only 8.3% (n = 1322) of the participants did not indicate any RRA-incidents. Nearly all of those (n = 101) had comparably small 'windows of opportunity' to encounter RRA since they either held positions with limited hours of contact with residents (e.g. as volunteers or kitchen staff) or had only recently started to work in the institution included in the survey.

Detailed information on the most recent RRA-incident observed was provided by 74.4% (n = 1197) of the participants. Mostly, incidents started in places where residents regularly meet other residents, such as dining rooms, hallways, or common rooms. In the majority of incidents specified, two residents (77.8%) had gotten into a conflict with each other. Just over 13.2% of the participants reported that three persons had been involved. In 9% (n = 855) of the last observed incidents, four or more residents were involved in the conflict. When asked for their views on possible triggers and causes of the last observed RRA-incident, participants (n = 872) mostly described that certain dynamics between residents lead to the conflicts: A resident felt disturbed (45.1%) or hassled (18.8%) by another or was jealous (13.2%) of another person; 31% stated that residents had an argument among each other. Often, a resident's poor capacity to communicate was named as the cause of the incident (resident was stressed because he/she could not understand a situation: 33.5%, resident was disoriented: 24%, resident had problems with speech/communication: 18.2%). Other possible triggers or causes for incidents indicated by participants were that a resident was impatient (29.1%) or anxious (7%) that his/her request was denied (3.8%), and that he/she felt disrupted by daily routines (5.3%). Noise in the residential area was mentioned in further 9.9% of the incidents as one (of the) cause(s), and in 12.4% participants stated, that the incidents occurred when staffing was insufficient or staff was under pressure of time (7.3%). Respondents often named multiple causes and triggers for the last observed incident, so figures add up to more than 100%.

Participants were also asked to provide information about the residents involved in this most recent incident (if there were more than two, the two persons considered to be most strongly involved were to be chosen). Characteristics can be compared between residents who–as perceived by respondents-started the argument (n = 673) and residents who did not start the argument (n = 576). They will be referred to as 'initiators' and 'targets' below.

The gender of initiators (68.1% female) and targets (75.9% female) involved in the arguments is in line with the overall sex ratio in German long-term care facilities (72% female, cf. Statistisches Bundesamt 2017, p. 8), though there is some over-representation of men being initiators and women being targets in the conflicts. There are barely any differences between initiators and targets regarding their age, apart from initiators belonging more often and targets less often to the group of the very old (80 years+: targets = 50.9%; initiators = 47.9%). Targets are more often limited in their abilities to communicate, to hear, or in their mobility, but cognitive loss is a characteristic present in both groups with around 60%. Among initiators, diagnoses of psychoses and addictions are more prevalent (but still only little under 10%), whereas targets are slightly more often diagnosed with dementia than initiators (62.3% vs. 55.4%).

13.6 Experiences with and Perceived Importance of Education and Training

Half of all participants (49.9%) had already learned about aggression and violence in nursing care as part of their job training. During the last 12 months, 27.1% of all participants (n = 1263) had attended trainings related to these topics. Among the key topics of these trainings, measures to 'handle aggressive resident behavior' were most frequent (16.8% of all topics mentioned by respondents), followed by 'causes and triggers' for (16.1%) and 'prevention' (13.3%) of such behavior (n = 334).

The vast majority of all participants (n = 1309) considered continuing education and training on aggression and violence in nursing care to be 'quite important' (25.5%) or 'highly important' (68.6%). They would like to learn more about techniques of de-escalation (76.1%; n = 1198) and safeguarding at the workplace (53.6%) as well as about coping with psychological stress caused by aggression and violence at the workplace (46.7%). So far, only 19.7% (n = 1264) had participated in some training on interacting with potentially aggressive persons. If participants had received relevant further education or training, approval of the perceived importance of such measures was even higher (n = 341): 77.1% considered them to be 'highly important', 20.2% said they were 'quite important' and only 2.6% considered them as just 'somewhat important' (overall sample: 5.7% plus 0.2% 'not at all important').

13.7 Findings from the Interview Study

The survey presented thus far has pointed out the high prevalence of RRA in German nursing homes and underlined the perceived importance of training staff to adequately respond to these more or less daily occurrences. The next section will focus on an in-depth view at opportunities and shortcomings of (further) training to handle RRA incidents adequately. The following results are derived from guided interviews with 42 interviewees, including 14 management staff and 28 qualified nurses and other staff (e.g. social workers, service staff, care assistants) in three nursing homes in the German federal state of North Rhine-Westphalia in 2017 and 2018.

Resident-to-Resident Aggression–A Disregarded Phenomenon Many interviewees reported episodes of RRA in which staff were, due to lack of training, were either not helpful or even themselves the source of the problem – because they did not deal with residents in a manner appropriate to their health and functional status, which made them nervous or aggressive, or because they were not able to identify aggressive cues and avert aggressive behaviour.

Most of the management and staff interviewed considered education and training to be highly important for working with residents, in particular when dealing with RRA. Many, however, expressed concern for the lack of training and skill, be it their own or others', when handling aggressive episodes. Both vocational and further training were described as lacking with regard to handling RRA episodes.

Vocational Training According to the interviewees, resident-to-resident aggression does not play a central role in the vocational training of nursing staff and other staff. Instead, the topic 'violence' is only covered briefly in training.

While most of the qualified nursing staff interviewed had been trained regarding aggressive behaviour between residents and staff, many felt helpless or insecure when observing incidents of RRA. As several interviewees thought, even the three-year training programme qualified nurses undergo does not necessarily provide the skills and competencies to handle resident-on-resident aggression.

Where even fully trained nurses lack expertise in handling RRA, assistant staff with little or no training were characterized by several interviewees as lacking skill and sensitivity when detecting and possibly averting residents' aggressive episodes. As one interviewee, a head nurse of a ward put it:

> Yes, definitely. This is-. It's obvious with colleagues who only have a two-year-training or often just a one-year training. Also with care assistants, they deal quite differently with the residents. Often you can prevent aggression by simply knowing the residents and simply paying attention to their reactions.

As the interviewee describes, less thoroughly trained staff often do not know how to interpret the residents' specific cues and are thus unable to prevent aggressive reactions.

Several interviewees spoke of a recent trend to focus qualified nursing staff on hands-on medical tasks, e.g. hygienic and medical duties, and leave the rest (look-

ing after the residents, paying attention and simply 'being there') to care assistants and other assistant staff. They considered this problematic, particularly with regard to RRA. Interviewees thought this separation leaves residents at many times in the sole care of poorly trained or untrained staff who are not equipped to detect specific aggressive cues, prevent escalation or intervene in violent situations among residents. As a social worker put it:

> […] And then they must, the staff surely need to be trained as well. For example, I still see opportunities for expansion, in general in the training of nursing assistants and nurses. Because we work with human beings and I have the expectation that we care properly for people, especially for those with dementia, and I don't think it's appropriate that we let rather untrained people do this work. This is a very, very sensitive topic and a very sensitive field of work. And people react very strongly, emotionally. Especially dementia patients. That's why aggression can happen, in fact. And those who have no knack for it and who lack a certain attitude und who might not even be properly trained, in my opinion they have no place in such an institution.

Further Training Programs As interviewees felt the basic training program lacked a focus on dealing with RRA, many of them thought the relevant skills needed to be taught in further training programs. Despite this perceived need for further training, however, several interviewees felt the further training courses available in their institutions were not adequately designed in order to prepare staff to handle aggressive incidents between residents. They said the programs had little or no focus on RRA, were not offered on a regular basis, or mostly addressed qualified nurses. According to many interviewees' experience, less qualified staff, who could profit most from further training, were either not among the target groups of existing trainings or they chose not to participate. Another matter pointed out by several interviewees was the lack of practical examples in basic and advanced training programmes: they felt the available training programmes were too general so that they failed to improve the skills of the staff when handling difficult situations like RRA.

Training and Capacity to Handle RRA Whereas RRA clearly is a highly important challenge for care institutions for older people, the staff interviewed reported a rather low level of competencies and skills in dealing with aggressive behaviour amongst residents. While many clearly see a need for education and training, not enough is currently done in the institutions that participated in our study. It can be assumed, moreover, that there is a certain participation bias: the institutions that agreed to participate and devote part of their staff's working time to the project are likely to face the problem in other ways as well, whereas institutions that refused to participate might be even less well prepared to deal with RRA. It can thus be assumed that having a greater focus on RRA during education and training would improve the staff's overall ability to detect, avert and handle aggression amongst residents. In particular, educating and training assistant staff seems crucial for them to be able to adequately perform their growing duties.

13.8 Conclusion and Implications for Institutional Policies

Resident-to-resident aggression is not merely a 'newly discovered' facet of elder abuse or elder mistreatment. Unlike elder abuse, it is not bound to relationships with an 'expectation of trust'[2] and has older care recipients on both sides of the victim – perpetrator dyad. Like elder abuse, it impacts health and quality of life and its frequency and intensity can be regarded as a quality indicator in institutional long-term care.

The survey among people providing work in German nursing homes shows that staff encounter both resident-to-resident aggression and residents' aggressive behaviour directed towards themselves. Four out of ten respondents have experienced physical aggression from residents during the last 4 weeks, and three out of ten have witnessed physically aggressive behaviour between residents during this short time frame. RRA episodes are often located in shared spaces within the nursing home (where they also have the greatest chance of being witnessed). Respondents name multiple causes and triggers for RRA, including individual characteristics, interpersonal dynamics, and physical and social features of the institutional environment.

Both the standardised survey and the interviews conducted in German nursing homes point at the key role of vocational training and continuing education for prevention and successful handling of RRA and aggressive incidents in general. Understanding of circumstances potentially leading to aggressive behaviour, detection of 'early warning signals', strategies of de-escalation and handling of violent incidents can be improved through training. At the same time, attention needs to be given to the design of the spatial environment (e.g. in order not to create spaces where crowding and violation of personal space are highly probable).

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[2] See the definition coined by WHO of elder abuse as 'a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person' (World Health Organization 2008 p. 6).

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Chapter 14
An Ecological Perspective on Elder Abuse Interventions

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14.1 Introduction

Elder abuse is a complex phenomenon which permeates all societies. As global aging occurs (WHO 2016), it is imperative that systems of safeguarding target both prevention and intervention. This chapter applies a socio-ecological lens to examine interventions within the published literature and is based on a study undertaken by the Irish National Centre for the Protection of Older People (NCPOP), University College Dublin (O'Donnell et al. 2015). The review included papers which described interventions using descriptive and qualitative designs as well as papers which evaluated the efficacy of interventions using experimental designs. The chapter commences with giving a brief review of elder abuse and then presents the findings of the NCPOP study (O'Donnell et al. 2015). The findings are categorized into descriptive and experimental designs and presented accordingly.

14.2 Elder Abuse

Based on a definition from Action on Elder Abuse (1995), a charitable organization in the United Kingdom, the World Health Organization (WHO) (2008) describes elder abuse as:

> a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person.

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While this definition provides some insight into what constitutes elder abuse, it does have limitations. Firstly, there is a focus on relationships, suggesting abuse is defined by the person who commits the act and not the act itself (Phelan 2018). Another challenge is that elder abuse, like beauty, can be in the eye of the beholder. For example, is abuse not abuse if there is no harm or distress to the older person? Other concerns center on the definition's over-inclusive nature (Brammer and Biggs 1998) and the lack of distinction of elder abuse and other forms of interpersonal conflict (Mowlam et al. 2007). This has led countries like Ireland to revise definitions to enable more clarity and to include a human rights dimension (HIQA 2013, Social Care Division 2014:8) as detailed below:

> … any act, or failure to act, which results in a breach of a vulnerable person's human rights, civil liberties, physical and mental integrity, dignity or general well being, whether intended or through negligence, including sexual relationships or financial transactions to which the person does not or cannot validly consent, or which are deliberately exploitative. Abuse may take a variety of forms.'

Since elder abuse's formal identification (Baker 1975; Burston 1975), understandings have increased with a delineation of typologies: physical abuse, sexual abuse, financial/material abuse, psychological abuse and neglect. The area of self-neglect has been contentious with its inclusion in some jurisdictions while being excluded in others (Phelan 2013). However, there are also differences in these categories when older people themselves define elder abuse (WHO and INPEA 2002; Erlingsson et al. 2005; Mowlam et al. 2007; Age Action Ireland 2011). In such studies, older people identify issues such as abuse of rights, social exclusions and compromization of decision- making (Phelan 2013).

In terms of the prevalence of elder abuse, it has been shown to occur in any setting (Naughton et al. 2010; Drennan et al. 2012). The WHO (2016), based on published prevalence studies, estimates that 1:6 older people are abused with a much higher prevalence in those who have cognition challenges and decision-making challenges (see Phelan and Rickard Clarke, Chap. 3, in this volume). As most older people live in the community, it is unsurprising that most abuse occurs in the home environment with family members being the most common abuser (Phelan 2018). Furthermore, psychological abuse (33%) is identified as the most common form of abuse with financial abuse and physical abuse constituting joint second (14%) (WHO 2016). However, individual studies vary from as low as 2.2% in Ireland (Naughton et al. 2010) to 18.4% in Israel (Lowenstein et al. 2009). It is likely that such studies are underestimates, with many cases being under-reported (Lifespan of Greater Rochester et al. 2011; Lachs and Pillemer 2015). Risk factors, with varying empirical support, have been identified as being related to the older person (physical and cognitive health, age, gender, financial dependency, ethnicity, dependency), the perpetrator (substance abuse, mental illness, dependency on the older person), relationship (victim and perpetrator, marital status), geographical location and societal norms (attitude to older people, cultural norms) (Kosberg and Garcia 1995; Phelan 2013; Pillemer et al. 2016; Yunus et al. 2017).

The consequences of elder abuse are diverse. These include social isolation, depression, anxiety (Dong et al. 2013) and suicide ideation (Wu et al. 2013). Abused

older people are more likely to report chronic pain (Fisher and Regan 2006) and being abused has been associated with a higher rate of admissions to hospital and long term care facilities (Dong and Simon 2013), as well as higher mortality rates (Schofield et al. 2013) and morbidity rates (Dong and Simon 2013, Fisher et al. 2011). In addition, there is a cost of addressing elder abuse within health budgets (Dong 2005; Jackson 2009a).

14.3 Responding to Elder Abuse Using a Socio-ecological Approach

In examining aspects of elder abuse, it is clear that it is a multi-faceted societal issue that has little evidence regarding interventions efficacy (Ploeg et al. 2009; Sethi et al. 2011; Stein 2017). However, there is an urgent need to have evidence-based interventions that are cost-effective and sustainable (Pillemer et al. 2016; Du Mont et al. 2015), particularly in the context of a global demographic shift to aging populations (O'Donnell et al. 2015). Consequently, responses are needed at multiple levels to address the total context of abuse perpetration. Yet, such robust evidence is elusive (Alt et al. 2011; Ploeg et al. 2009). Using a socio-ecological model (Bronfenbrenner 1979) has the advantage of targeting understanding and responses from the microsystem of the older person's immediate environment to the macrosystem of the policy and legislation. Bronfenbrenner (1979) initially used the lens of a socio-ecological model in child protection arguing that a child is immersed in complex systems (microsystem, mesosystem, exosystem, macrosystem and chronosystem) which interact with each other and can either heighten risk or safeguard the child. Since then, the socio-ecological model has been applied to the domain of elder abuse (O'Donnell et al. 2015; Dow et al. 2018) and the sphere of family violence in general (Dahlberg and Krug 2002; WHO 2018; Centre for Disease Control and Prevention 2018). We adapted Bronfenbrenner's (1979) model to represent a systems level intervention as presented in Table 14.1. As the majority of the literature represented single point studies, we omitted the chronosystem as this represents a change over the time dimension.

14.4 Identifying the Literature: Systematic Search Strategy

In this chapter, we draw on work undertaken in the National Centre for the Protection of Older People (O'Donnell et al. 2015). Within this study, we undertook a search of nine databases (EBSCO (Academic Search Premier, CINAHL, Lista), PubMed (Medline), Web of Science (Social Science/Science Citation/Arts and Humanities), OvidSP (Medine/PsychInfo) for the period of January 2000–October 2013. Both single and combination terms were used for elder/old, intervention, prevention, care

Table 14.1 Adapted Bronfenbrenner's (1979) model to elder abuse interventions (O'Donnell et al. 2015)

Systems-level	Categorization
Microsystem	Interventions directly targeting the older person who is or is at risk of experiencing abuse within immediate contact, for example, home environment, residential care home, community.
Mesosystem	Interventions that target the connections between the micro-systems (family, friends, community group). This system also included interventions which involved caregivers (formal and informal), family, social network and community networks.
Exosystem	Interventions which include links between the individual's immediate context and a social setting within which the individual does not have an active role (adult protective service, criminal justice systems, social welfare system, health system, political system)
Macrosystem	Interventions that focused on the over-arching culture, such as values and beliefs of societies, socio-economic status, identity and heritage, and discriminatory social values that foster abuse.

and service. MeSH terms for elder abuse and mistreatment were also used. Additional strategies were used to include previous systematic reviews, manual searching of the National Centre for the Protection of Older People's database and ancestral searching was used to enhance the literature search. Using the World Health Organization (WHO) (2008) definition of elder abuse, only English language texts were reviewed and 'older people' related to those over 50 years of age. Retrospective and prospective studies were included as well as studies using an experimental or descriptive design. Screening tools, book chapters, book reviews, systematic reviews, strategy reports and literature appraisals were not included. This resulted in 7170 citations, of which 5417 were eliminated due to not being relevant or ineligibility. Of the remaining 1753, 1545 were eliminated through a review of title and abstract. A full-text read of the remaining 208 articles eliminated a further 104 publications. The remaining 104 were included in the review of which 67 were identified as non-experimental descriptive studies and 37 experimental studies.

14.5 Categorizing Retrieved Interventions

Following the literature reduction, each article was carefully read and categorized into the adapted Bronfenbrenner (1979) model as detailed in Table 14.1. Two researchers engaged in inter-rater reliability of categorization. As some papers represented the same intervention (i.e. intervention resulted in more than one publication), the review identified 98 unique interventions. If any publication had interventions which spanned the systems, the researchers agreed on placement in a dominant system (Table 14.2).

Table 14.2 Systems levels and study design type

Systems level	Experimental design	Descriptive design	Total
Microsystem	5	13	18
Mesosystem	25	27	52
Exosystem	3	20	23
Macrosystem	1	4	5
Total	34	64	98

The evaluation of the descriptive designs followed Jackson's (2009b) criteria for presenting the phenomenon as it naturally occurs. Descriptive designs contained case studies, discussion papers, observational studies, program evaluation surveys and papers on service reform or educational initiatives. Experimental design papers were evaluated using Rychetnik et al.'s (2002) evaluation of public health interventions which examines if the research design was good enough, what were the research outcomes and is the research transferrable.

14.6 Microsystem

A total of 18 papers were included in the microsystem level, which encompassed interventions that directly involved the older person. Within the descriptive design papers, these included a review of individual case management, which could be general elder abuse cases or specific typologies (Heath et al. 2005; Istenes et al. 2007; Morris 2010; Vladescu et al. 2000) or case relating typologies (Koenig et al. 2010; Malks et al. 2002; Sacks et al. 2012) to gender (Tetterton and Farnsworth 2011). While most focused on responses to elder abuse being perpetrated, one paper discussed an intervention that had a preventative focus (Alon and Berg-Warman 2013).

Another intervention included creating referrals into *Linking Geriatrics to Adult Protection (LGAP)* to concurrently address unmet health needs in addition to safeguarding needs. Following the assessment of the older person's case, five interventions were available, which included guardianship, hospital admission, home help, institutional placement or medication initiation. Of the older people referred, 81% required one or more intervention and guardianship and institutional placement were found to have significance for case management. A similar intervention in Colorado, the *Team Elder Abuse Mistreatment Project* of Summit County also provided an interagency approach (geriatrician, social worker, probate court investigator, sheriff's department, aging agency, adult protective service) (Istenes et al. 2007). Although the sample case size was small, the study reported a 100% case success. Having a dedicated support service, specializing in elder law (Morris 2010) was also identified as reducing the older person's stress as well as making the legal engagement more efficient. Equally, Vladescu et al. (2000) reported on an

empowerment-based intervention, however, it was noted that the increased length of time on cases in this *Seniors' Case Management Programme* did not correlate to increases in positive case outcomes.

Koenig et al. (2010) presented an ethical framework for managing cases of older adults who were hoarders, however, it was propositional in nature and would require practical implementation and evaluation. In exploring cases of abuse of older women, Tetterton and Farnsworth (2011) emphasized the building of rapport to underpin therapeutic relationships, however, the paper was based on only two elder abuse cases.

Malks et al. (2002) examined the multi-disciplinary *Financial Abuse Specialist Teams (FAST)* which had the discretion to freeze assets when financial abuse was suspected and undertake investigative activities. The authors acknowledged that multi-disciplinary collaboration and staff support were essential to the program's success. There was a rise of referrals by 60%, demonstrating efficacy. Similarly, Sacks et al. (2012) examined the impact of *Daily Money Management* programs from eight private non-profit agencies providing such services and suggest that such programs can act as a deterrent to the older person experiencing financial abuse. Combatting tele-fraud through the National Telemarking Victim Fraud Centre was examined in a study by Aziz et al. (2000). This intervention applied proactive targeting of older people whose names were listed in a MOOCH list. A MOOCH list holds information on people vulnerable to financial abuse and can be sold on for further exploitation. In the first year, almost 20,000 calls were made and there were 68 older people who had received fraud-related calls, however, the study did not explore the impact of preventative education.

A total of five experimental evaluation studies were retrieved and categorized in the microsystem ecological level (Acierno et al. 2004; Dyer et al. 2002; Filinson 1993; Mariam et al. 2015; Wilber 1991). The five interventions classified at this ecological level were:

- a 15-min educational video and corresponding brochure aimed at educating older people who experienced criminal victimization, as to healthy coping and safety planning strategies (Acierno et al. 2004);
- an interdisciplinary geriatric assessment and intervention program which targeted the psychological and social well-being of patients referred by adult protective services (Dyer et al. 2002);
- a volunteer advocate program which provided assistance and advocacy to older people experiencing abuse with a particular focus on providing support in the utilization of the criminal justice system (Filinson 1993);
- a program which sought to mobilize the social and psychological resources of older people considered at risk of abuse and/or self-neglect by targeting their relations with family and their community (Mariam et al. 2015);
- and a daily money management program which sought to divert older people, referred to protective services, from conservatorship (Wilber 1991).

Three of the studies evaluated interventions using an experimental design, which incorporated a comparative control group (Acierno et al. 2004; Filinson 1993;

Wilber 1991). Two of the studies employed a quasi-experimental design, typically a pre and post-intervention evaluation, to generate evidence for intervention efficacy (Dyer et al. 2002; Mariam et al. 2015).

14.6.1 Summary

While some positive outcomes were found in the descriptive studies, in considering the literature presented in relation to microsystems' level, it was concluded that evidence to support any particular intervention at this ecological systems level was weak in relation to the small samples sizes, risk of bias, intervention implementation and outcome measurement (O'Donnell et al. 2015). This highlights the need to further robustly examine the potential of microsystems interventions to safeguard older people at risk of or experiencing abuse.

Of the five experimental papers included for review which were classified at this ecological systems level, the strongest evidence for efficacy was found for a psychological and social support intervention targeting at-risk older people (Mariam et al. 2015) and an educational video and corresponding brochure aiming to educate older people who experienced criminal victimization (Acierno et al. 2004).

14.7 Mesosystem

The mesosystem included interventions which had an impact on the older person but did not involve direct contact and tended to be evaluations of programs. This systems-level contained the highest number of elder abuse interventions (n = 52).

For the descriptive studies (N = 27), these can be sub-divided into case management service models and educational initiatives, while the experimental design was sub-divided into support groups for older people, interventions targeting perpetrators, interventions targeting informal caregivers, interventions targeting first responders, interventions targeting nurses and nursing assistants, interventions targeting physicians and interventions targeting multi-disciplinary healthcare providers.

14.7.1 Case Management Service Models

Service models which provided elder abuse training and specialist response systems were shown to be important in terms of raising staff awareness and effective case management and the identification of appropriate pathways which mapped to the abuse severity and type (Alon and Berg-Warman 2013; Wolf and Pillemer 2000) as well as family systems and risk management approaches. Interventions could include counseling, support groups, day care, home care, medical treatment or legal

support, however, functional impairment impacted on achieving case resolution, while addressing caregiver stress was important (Wolf and Pillemer 2000). In Alon and Berg-Warman's (2013) Israeli study involving three municipalities, a *Specialized Unit for the Prevention and Treatment of Elder Abuse* (SUPTEA) was established which comprised of a social worker and paraprofessional linked to an advisory multi-disciplinary team. The were two objectives-screening for risk and the provision of interventions such as one to one counseling, family mediation and group work. A second focus was public awareness raising. In tandem with SUPTEA, 40 social workers received two elder abuse training programs. The evaluation was undertaken through questionnaires (N = 558, social workers) and interviews (abusers, victims, professionals) and observations of group work. Findings pointed to improved case management procedures and the closure of almost a third of cases, with a further resolution in 18% of cases.

Wolf and Pillemer (2000) explored case management in 59 cases of elder abuse in three elder abuse response programs. Findings pointed to the importance of case variables such as abuse severity, the stress of the older person and perpetrator and type of abuse. Intervention success also relied on approaches to self-determination, family preservation and openness to the intervention by the family. The authors, based on the findings, pointed to the importance of a family systems approach to case intervention (Wolf and Pillemer 2000).

Having a variety of professionals within a dedicated multi-disciplinary team was considered particularly useful as each member brought their disciplinary experience to cases and working together increased communities of practice in responding to the myriad of complexities inherent in elder abuse (Teaster et al. 2003; Twomey et al. 2010). However, having good leadership with multi-disciplinary co-ordination and participation was essential. In particular, multi-disciplinary working could also enhance medical assessment, law enforcement investigation and legal processes as services (Mosqueda et al. 2004; Navarro et al. 2010). In terms of legal intervention, specialist legal services were considered a positive response to managing and raising awareness of elder abuse (Velasco 2000). Legal intervention was also found to be significant in the cessation of the abuse as perpetrators were held responsible (Jackson and Hafemeister 2013). Having a multi-disciplinary response to financial abuse was considered particularly important as this form of abuse is the only category that is not necessarily within the typical domain of health and the immediacy of the individual's body but involves other sectors (such as financial institutions and social protection departments). Aziz et al. (2000) examined the work of the *Fiduciary Abuse Specialist Team (FAST)* in Los Angeles and found that the team's work resulted in increased awareness of financial abuse as well as having optimum and speedy outcomes.

Jackson and Hafemeister (2013) interviewed adult protective service caseworkers (N = 71), older victims (N = 51 and third party persons (N = 35) to examine if a change in living arrangements, the appointment of a guardian, continuing contact with the abuser, perceptions of future risk and consequences for abusive individuals were important in abuse continuation after case referral. Findings demonstrated that continued living with the abuser and the absence of negative sanctions on the abuser impacted prolonging the maltreatment.

Reis and Nahmiash (1995) evaluated the multi-disciplinary team approach (screening tool package, responsive intervention team) in *Project Care* for 218 abused older people demonstrating similar findings to the studies above; however, they also examined the implementation of a social capital approach through the availability of a volunteer buddy system who worked with both the older people and the perpetrator, a support group and a community level advocacy group. Findings demonstrated that these approaches were both cost-effective and underpinned effective care management.

Similarly, the mobilization of community within a restorative justice framework was applied as an alternative management model for elder abuse which involved a skilled facilitator and focused on conflict management and resolution (Groh and Linden 2011). While the project was judged successful and increased collaboration, highlighting both general awareness and the older person's voice and developing robust networks, it was noted that it involved a greater than anticipated amount of resources, time and additional training and that it was only suitable for some cases of elder abuse (Groh and Linden 2011; Stones 2004), thus constituting an option pathway within traditional services (Linden 2006). Other challenges concerned the low volume of case referrals and the difficulty in recruiting 'neutral' family members to become involved.

Another descriptive study by Holkup et al. (2007) was conducted with native American Indians facilitating responses within their own community. Findings pointed to the importance of integrating a culturally compatible response model which would be acceptable to the population being assisted.

Brandl et al. (2003) and Seaver (1997) examined the impact of support groups (mainly for women) and found such groups could reduce the older person's sense of social isolation and provided communities of support. However, both studies acknowledged the imperative of having a contextual understanding in case management which included an appreciation of the inherent ethical dimensions of the abuse.

Several studies examined the role of education in knowledge transfer for professionals, with Gironda et al. (2010) identifying health care professionals' limited understanding of elder abuse management. Education initiatives focused on health care assistants/aides (Hudson 1992; Radensky and Parikh 2008), nurse assistants/aide students (Smith et al. 2010), nursing students (McGarry and Simpson 2007), public health nurses and social workers (Day et al. 2010), social work students (Corley et al. 2006), dentists (Harmer-Beem 2005), multi-disciplinary professionals (dentistry, emergency medical technicians, health care interpreters and community workers, coroners, medical examiners) and advanced training for Adult Protective Services (Gironda et al. 2010; Teitelman and O'Neill 2000). Many of these programs indicated that, following specific educational interventions, there was increased awareness and clarity around the topic (Hudson 1992, Radensky and Parikh 2008), increased understanding of their individual disciplinary roles and inter-professional collaboration (Day et al. 2010; Heath et al. 2002) and the inherent ethical responsibilities of case management (McGarry and Simpson 2007). Other findings identified that mandatory reporting figures could be improved (Harmer-Beem 2005, Radensky and Parikh 2008) as well as increasing confidence in managing cases of sexual abuse (Teitelman and O'Neill 2000) and highlighting the

importance of integrating elder abuse topic and case management content into educational programs (Corley et al. 2006).

Other educational programs targeted professionals outside health and social care. For example, Proehl (2012) delivered an educational program to clergy, which increased community awareness and strengthened networks, while also reducing the fear of reporting to adult protective services. However, the sustainability of such programs requires appropriate leadership in the community.

The majority of the research papers retrieved from the literature search, which empirically evaluated interventions using an experimental design, were classified under the mesosystem ecological level. A total of 25 interventions evaluated in 27 peer-reviewed research papers using an experimental research design were identified as pertaining to the mesosystem ecological level. These were divided into seven different categories: support groups for older people including survivor groups (n = 2); interventions targeting perpetrator behavior (n = 2); and interventions which targeted caregivers, including informal carers (n = 3), nurses and nursing assistants/aides (n = 6), physicians (n = 5), first responders (n = 2) and other types of formal healthcare professionals, such as dentists (n = 5).

14.7.2 Support Groups for Older People

Bowland et al. (2012) undertook a randomized controlled experiment evaluating the efficacy of a spiritual therapeutic group intervention with older women survivors of interpersonal violence (N = 45). In this experiment, a significant positive effect was found for the intervention on the outcome measures of depressive symptoms, anxiety and physical symptoms. These positive effects were maintained at a three-month post-intervention follow-up.

Brownell and Heiser (2006) undertook a randomized controlled experiment evaluating the efficacy of a psycho-educational support group with older female victims of family mistreatment (N = 16). The outcomes measured in the assessment of intervention efficacy included: locus of control, social support, depression, somatization and guilt. No significant effect was found for the intervention on any of the outcome measures.

14.7.3 Interventions Targeting Perpetrator Behaviour

Campbell Reay and Browne (2002) undertook a non-randomized quasi-experiment (pre and post-test) design to evaluate the efficacy of an education and anger management program among a sample of perpetrators of elder abuse (N = 19). The authors reported a significant effect for the training post-intervention and at 6 weeks follow-up for the outcome measures of strain, depression and anxiety. Furthermore,

a significant effect was also found for the cost of care as well as conflict tactics and reductions in these measures were maintained at 6 weeks follow-up.

Scogin et al. (1990) evaluated the evidence for the efficacy of a caregiver training program targeting caregivers found to be abusive or at risk of abuse (N = 95) using a non-randomized control/intervention comparison design. The authors concluded that cognitive behavioral training can reduce psychological distress and perceptions of the cost of care among potential perpetrators of abuse.

14.7.4 Interventions Targeting Informal Caregivers

Drossel et al. (2011) employed a quasi-experimental (pre and post) design to evaluate the evidence for the efficacy of an intervention providing dialectic behavior therapy skills training to non-professional caregivers of people with dementia (N = 16). The authors found a positive effect for the intervention on psycho-social adjustment, specifically increased problem-focused coping, enhanced emotional well-being and less fatigue.

Hébert et al. (2003) undertook a multi-center randomized controlled experiment to evaluate the efficacy of a psycho-educative group program targeting caregivers of people with dementia (N = 118). The outcome measures used by the authors to evaluate efficacy included self-perceived health, care recipient's disease and caregiving issues. The authors found a significant effect post-intervention for their psycho-educative program targeting caregivers of people with dementia on the outcome measures of reaction to and the frequency of behavioral problems of care-recipients. No effect was found on more global outcome measures of stress, psychological distress, burden and social support.

Phillips (2008) evaluated the efficacy of psycho-educative nursing intervention using a randomized controlled experiment which measured intervention effect on the frequency and intensity of physical and verbal/psychological aggression toward older caregiving wives and daughters (N = 83) by care recipients. The authors found evidence which supported the efficacy of the intervention in reducing the verbal aggression experienced by caregivers of older men. Furthermore, these caregivers experienced significantly less depression, anger and confusion following the intervention. However, this effect was not found for caregivers of older women and the intervention was found to have no significant effect on the experience of physical aggression, disruptive behavior and social function.

14.7.5 Interventions Targeting Nurses and Nursing Assistants/ Aides

Braun et al. (1997) evaluated a short-course educational program aiming to prevent elder abuse that may arise within the nursing relationship as a result of professional burnout, resource constraints or stress. They employed a quasi-experimental (pre and post) design using a sample of nurses' aides working in a nursing home (N = 105). Their study found a positive evaluation of the learning materials by the participants with a significant increase in job satisfaction post-intervention.

Désy and Prohaska (2008) described and evaluated the *Geriatric Emergency Nursing Education (GENE)* course providing education and training on geriatric nursing, which included a module on the identification, management and reporting of elder abuse and neglect. They employed a quasi-experimental (pre and post) design with a sample of emergency nurses (N = 63) and found a positive effect for the intervention on knowledge of geriatric concepts and self-rated ability to provide care in a number of relevant areas including appropriate referral to protective services.

Goodridge et al. (1997) evaluated a specific abuse prevention program which was designed and developed by the *Coalition of Advocates for the Rights of Infirm Elderly (CARIE)*. They evaluated the efficacy of this program on a sample of nursing assistants (N = 136) in a long-term care facility using a quasi-experimental (pre and post) design. The program was positively evaluated by the nursing assistants and the pre/post tests indicated a positive effect for the intervention in terms of the sample's attitudes towards older patients and a significant decline in self-reported nursing assistant-resident conflict.

Hsieh et al. (2009) employed an experimental design incorporating a comparator control group to evaluate the efficacy of an educational support group program for geriatric caregivers. This case-control study recruited caregivers (N = 100) from four nursing homes in southern Taiwan. The experiment found a significant positive effect in reducing psychological abusive behavior by caregivers and promoting knowledge of geriatric care giving. However, no significant effect was found for reducing work stress.

Pillemer and Hudson (1993) evaluated a specific abuse prevention program which was designed and developed by the *Coalition of Advocates for the Rights of Infirm Elderly (CARIE).* They employed a quasi-experimental (pre-post) design with a sample of nursing assistants (N = 114) randomly selected from 10 nursing homes. The evaluation of the CARIE program found a significant positive effect for evaluations of the intervention as well as improvements on a number of indicators, including reduced conflict with and abuse of residents.

Teresi et al. (2013) evaluated an intervention which sought to reduce resident to resident elder mistreatment in an institutional setting through awareness raising and training of nursing staff in appropriate prevention and management strategies. They employed a clustered randomized trial, randomized at facility level with matched controls, targeting certified nursing assistants and measuring outcomes on residents

(N = 1405) randomized into a control and intervention group. The authors found a significant positive effect for the intervention on knowledge and recognition of resident to resident elder mistreatment. Furthermore, there were significantly increased levels of reporting of mistreatment among the intervention group.

14.7.6 Interventions Targeting First Responders

Nusbaum et al. (2006) and Nusbaum et al. (2007) measured the effect of a workplace education program on attitudes and behaviors of police and firefighters responding to a situation of potential elder abuse. The authors employed a quasi-experimental (pre and post) design over three-time points to measure the effect of an intervention which aimed to increase awareness and detection of neglect and abuse of older people among police and firefighters (N = 101). The authors found no significant effect for their intervention and concluded by highlighting the difficulty of using educators external to an organization to drive attitudinal and behavioral change.

Seamon et al. (1997) undertook a quasi-experiment (pre and post) to evaluate the efficacy of a 45-min training video on improving the ability of pre-hospital emergency medical service personnel (N = 60) to identify and report suspected cases of elder abuse. The outcomes measured in the experiment included identification of elder abuse and neglect, willingness to report suspected cases, definitions of elder abuse and neglect and mandatory reporting requirements. The authors found evidence to support the efficacy of their educational video.

14.7.7 Interventions Targeting Physicians

Cooper et al. (2012) evaluated evidence for the efficacy of a short group educational program on trainee psychiatrists (N = 40) using a quasi-experimental (pre and post) design undertaken at three-time points. The authors found evidence to support the efficacy of the intervention in increasing recognition of abusive caregiving strategies as well as knowledge of the management of elder abuse.

Famakinwa and Fabiny (2008) evaluated the efficacy of a small group teaching session on the topic of caregiver stress delivered to medical residents (N = 40) using a quasi-experimental (pre and post) design. The authors reported that significant positive effect was found for the intervention on recognition of elder abuse and an understanding of caregiver stress.

Jogerst and Ely (1997) undertook a case/control non-randomized comparison of family practice residents in order to evaluate the efficacy of a home visit program,

which was delivered as part of a geriatric rotation. The aim of the program was to enable family practice residents to evaluate patients for elder abuse and capacity in their homes. The authors reported a positive effect of the program on residents' self-rated ability to diagnose elder abuse and assess a patient's home environment post-intervention.

Shefet et al. (2007) evaluated the efficacy of a national domestic violence experiential training program based on standardized patients to improve the knowledge, skills and detection rates of primary care physicians (N = 74). The program pertained to three areas of domestic violence, one of which was elder abuse. The authors reported a positive significant effect on the intervention in self-perceived capabilities and overall case management of domestic violence among participants.

Uva and Guttman (1996) evaluated the efficacy of a 50-min education session on elder abuse with emergency medical residents (N = 31) using a matched controlled survey. The outcome measures used to assess efficacy pertained to knowledge of elder abuse and self-rating of the intervention. The authors reported a significant positive effect for the intervention on elder abuse knowledge post-training and at 1-year follow-up.

14.7.8 Interventions Targeting Multidisciplinary Healthcare Providers

McCauley et al. (2003) created and evaluated a multi-disciplinary continuing medical education videotape on interpersonal violence (ASSERT), which incorporated a module on elder abuse. They employed a quasi-experimental (pre and post) design with a sample of physicians (N = 120) and other healthcare providers including nurses and social workers (N = 172). The authors found a significant level of improvement for knowledge and attitudes towards interpersonal violence and the intervention was rated positively by the participants.

Mills et al. (2012) evaluated evidence for the efficacy of an education program concerning elder investment fraud and financial exploitation. The program targeted a range of healthcare professionals (N = 127), including physicians, nurses, social workers, occupational therapists and physiotherapists. The outcomes measured to assess efficacy included self-assessed ratings of the program as well as the implementation of program material into practice, specifically the number of elder abuse cases identified 6 months post the intervention. The authors reported a positive effect for the intervention using summary descriptive statistics.

Using a randomized controlled trial Richardson et al. (2002) and Richardson et al. (2004) evaluated the efficacy of attendance at a short educational course on managing elder abuse with healthcare staff (N = 64), including nurses, care assistants

and social workers. The authors reported a significant positive effect for the intervention on knowledge and management of abusive scenarios.

Sugita and Garrett (2012) evaluated the efficacy of an intervention to increase knowledge and self-perceived likelihood to report elder abuse among oral healthcare providers (N = 103). They conducted a quasi-experiment (pre and post) and reported post-intervention increases in awareness of reporting processes, knowledge and awareness of elder abuse, knowledge of mandated reporter requirements and increased recognition of elder abuse.

Vinton (1993) evaluated an elder abuse and neglect prevention education program on a mixed sample of caregivers (N = 107), which included homemakers, personal care aides, respite workers, case managers, administrators, nurses, social workers and law enforcement officers. They undertook a quasi-experiment (pre and post) and concluded that case managers showed the most improvement in their knowledge of elder abuse law as well as the nature of elder abuse and the principles that guide protective services.

14.7.9 Summary

What is clear from the review of the descriptive studies in the mesosystem is that successful case management is dependent on having responses tailored to the case. While some studies had small sample sizes, there was an impact in the initiatives related to both case management and educational programs. In particular, case management demands good leadership and the effective collaboration of multidisciplinary teams. Community awareness is also important as well as the involvement of community-level groups, such as faith groups and others to raise the issue of elder abuse and introduce it into their members as a topic of concern. The educational interventions within the descriptive studies highlighted the need to spend time and reflect on cases to effectively navigate their complexities. Educational interventions were shown to increase case referrals and case efficiency, while the clarity of responsibilities (ethical, practice professional, mandatory reporting) were enhanced, particularly when using case scenarios (Day et al. 2010; Heath et al. 2002) as a learning method. Educational programs were also evaluated as good interventions for members of organized religion and faith communities and strengthened community social capital in responding to elder abuse.

Overall the level of evidence for the experimental research designs used to evaluate the 25 interventions identified in this study and classified under the mesosystem category was found to be weak (O'Donnell et al. 2015). The majority of the studies were evaluated as being at risk of bias, with poor intervention implementation and outcome measurement. None of the interventions which targeted support or survivor groups for older people (n = 2), perpetrators (n = 2), physicians (n = 5) or first responders (n = 2) was found to have a high level of evidence quality to support efficacy (O'Donnell et al. 2015).

In relation to interventions which targeted informal caregivers (n = 3), two were found to have a good evidence base to support their efficacy (O'Donnell et al. 2015). These interventions included a psycho-educative program targeting caregivers of people with dementia using the outcome measures of reaction to and the frequency of behavioral problems of care-recipients (Hébert et al. 2003). There was also high-quality evidence to support the efficacy of a psycho-educative nursing intervention in reducing the verbal aggression experienced by caregivers of older men as well as reducing caregivers' experiences of depression, anger and confusion (Phillips 2008).

One intervention which targeted nurses or nursing assistants/nurses' aides were found to have a strong evidence base to support efficacy (O'Donnell et al. 2015). A very high rating was assigned to the quality of the evidence supporting an intervention which sought to reduce resident to resident elder mistreatment in an institutional setting through awareness raising and training of nursing staff in appropriate prevention and management strategies (Teresi et al. 2013). Of the five interventions that targeted multi-disciplinary healthcare providers, the strongest evidence for the efficacy of intervention was found for a short educational course on managing elder abuse (Richardson et al. 2002, 2004).

14.8 Exosystem

The exosystem represents a step further from the immediate environment of the older person and is constituted by various service levels, such as adult protective services, the criminal justice service, the social welfare system, the political system as well as educational and health systems. In total, 32 papers were categorized into the exo-system. There were 28 papers categorized in this system related to descriptive studies; 14 were related to evaluations of systems of service delivery, 9 related to the criminal justice system and 5 belonged to systems process improvement. There were four papers presenting three interventions which were classified under the experimental studies.

14.8.1 Evaluation of Systems of Service Delivery

In the evaluation of systems of service delivery, the development of adult protective services in the United States had not received the same interest as other areas of family violence (Dyer et al. 2005). Some of the papers reviewed presented a description of services rather than evaluation (Dyer et al. 2005; Kaye and Darling 2000; Reingold 2006; Solomon and Reingold 2012) and supported a multi-disciplinary and inter-setting collaboration (adult protective services, criminal justice system, health care assessment) in responding to elder abuse. Within service descriptions, Dyer et al. (2005) describes the activities of the adult protective services in case management and considers the pathways available to respond to the individual

aspects of the older person's abuse. The Weinberg Centre (Reingold 2006, Solomon and Reingold 2012) offered a continuum of elder abuse intervention services such as a toll free number for information, community based team, emergency center assessment, a medical day program and pathways to return to community or placement in long term accommodation comprised of apartments or residential care admission. Kaye and Darling (2000) also provided a description of the state of Oregon's Attorney General's task force to respond to financial exploitation of older people. This involved training for bank staff, an elder abuse prevention program targeting older people, enhancing telephone safety and awareness of MOOCH lists and their function.

Teaster and Wangmo (2010) reviewed 32 multi-disciplinary elder abuse local coordinating councils on elder abuse in Kentucky. Findings pointed to the identification of appropriate services, awareness raising, training and advocacy, although there was a lack of service standardization in policy documents and the authors noted the need to have appropriate structural, human and financial resources. Different service models (crime victims approach versus social support) did not demonstrate any advantage in terms of outcomes, however, having access to legal and social supports was considered fundamental in tailoring responses to individual cases (Brownell and Wolden 2002; Sengstock et al. 1991). In Ernst and Smith's (2012) study, the financial cost of having a nurse-social worker team as opposed to a lone social worker was not justified, while in another study, the intervention of adult protective services in the United States was found to greatly increase the risk of nursing home admission (Lachs et al. 2002). For people living with dementia, a study in Cleveland demonstrated that having adult protective services working with the Alzheimer's Society increased cross-service collaboration but also emphasized the need to understand each organizations' roles and responsibilities as well as developing successful communication channels (Anetzberger et al. 2000).

Tools and training to assist decision-making and reporting were also evident in the literature. For people who have cognitive capacity challenges, Horning et al. (2013) developed a decision-making flow chart to assist clinical staff's management of financial abuse and to guide decisions on interventions needed, however, this was not evaluated.

Informal community networks were seen to empower older people to assert rights (Cripps 2001) while the need to have family centered therapy and mediation to address relevant case issues both historical and current was recognized (Bergeron 2002; Wall and Spira 2012).

14.8.2 Criminal Justice System

Increasing knowledge and collaboration was considered important in relation to elder abuse within the criminal justice system and the police service. Studies described enhancing legislative responses to elder abuse, training for law enforcement staff and having specialized case management processes (Heisler 2000). In

reviewing the relationship between adult protective services and criminal justice professionals, Blakely and Dolon (2001) found that collaboration with police was helpful in case management, however, challenges were noted in relation to working with victims' assistants due to a lack of explicit disciplinary relationships. Community awareness and professional knowledge of elder abuse statutes, particularly related to mandatory reporting, was important and increased investigation rates (Daly et al. 2003; Jogerst et al. 2003). However, mandatory reporting could disempower the older person and negatively impact the clinician-older person relationship (Lai 2008; Rodriguez et al. 2006). Equally, while systems of guardianship were framed to act in the older person's best interests, there was potential for abuse and safeguards need to be in place to ensure decisions made by the guardian are not biased (Black 2008; Kohn 2006). Consequently, legislation needed to provide for protective safeguards for older people in addition to sanctions for people who abuse legislative powers such as guardianship. In an attempt to improve medical documentation for legal cases, Koin (2003) described the development of a bespoke medical examination form which incorporated examination of cognition, consent, pain assessment and case contexts. The examination form was developed for health professionals who had special forensic training in elder abuse as well as other professionals such as nurses, physicians and assault specialists.

14.8.3 Systems Process Improvement

System process improvement studies involved publication within which response systems were examined within the context of serious case reviews of practice failures in responding to cases of abuse. In the United Kingdom, Cambridge et al. (2011) review more than 6100 case referrals and concluded that having specially trained adult safeguarding coordinators was shown to improve both process and outcomes in case management in terms of more comprehensive investigations and joint collaboration with other agencies (Cambridge et al. 2011). Noting the lack of case standardization, a 2-day training program on decision making for choosing appropriate elder abuse interventions and a data monitoring system was considered as enabling case management consistency (Cambridge and Parkes 2004).

The final study included in systems process improvements involved interviews with ten members of safeguarding boards and four independent chairs of serious case reviews (Manthorpe and Martineau 2012). Findings revealed that serious case reviews contributed to organizational learning, however, there was a tension in the conduct of the reviews between a no blame focus and potential negligence. Findings pointed to the value of an independent chair, while also highlighting the need to have a better underpinning legislative basis to improve information gathering and process.

Three interventions which were evaluated using experimental research designs were identified as pertaining to the exosystem ecological level (Davis and Medina-

Ariza 2001; Davis et al. 2001; Jogerst et al. 2004; Navarro et al. 2013). The three interventions, which were described in four peer-reviewed articles, and classified at the exosystem level were:

- a community level intervention aimed at reducing repeat incidences of elder abuse through a public education program combined with targeted home visits from law enforcement and social workers (Davis and Medina-Ariza 2001; Davis et al. 2001);
- compulsory training for mandated reporters in the state of Iowa, USA (Jogerst et al. 2004);
- an elder financial abuse forensic centre providing multi-disciplinary consultation for complex cases of elder financial abuse (Navarro et al. 2013).

Two of the studies employed a case-control matched design (Jogerst et al. 2004, Navarro et al. 2013) and the third study evaluated efficacy using a nested randomized controlled design (Davis and Medina-Ariza 2001, Davis et al. 2001).

14.8.4 Summary

Within the descriptive studies, it is difficult to determine the actual impact of interventions for those that simply described services without any rigorous evaluation. While describing services gives information on bespoke interventions, there is a substantial gap in assessing how successful these interventions are in addressing elder abuse within issues of economics, the acceptability of service responses, replicability, outcomes and other criteria. Other studies which did apply evaluation methods identify advantages such as emphasizing the importance of community support, enhanced inter-agency collaboration and networking, reduction of risk, availability of resources, awareness raising, but also some limitations, such as a lack of standardization or a lack of funding, dysfunctional inter-agency collaboration and a cost limitation in comparison to other elder abuse service delivery models. One study (Lachs et al. 2002) pointed to the higher risk of nursing home placement for older people referred to adult protective services. While this may place the older person in an environment of 'safety', it is possible that this impacts the happiness of the older person, who may have wanted to remain at home. Moreover, having robust, standardized systems in place is important and these should have legislative foundations, as well as independent chairs, which were seen as important in serious case reviews of abuse.

Overall the level of evidence found to support the experimental interventions identified at this ecological systems level was reasonably high (O'Donnell et al. 2015). All three papers employed a control or comparator group in their experimental design. Two of the studies rated fairly well in relation to the strength of the evaluation design in terms of risk of bias, intervention implementation and outcome measurement (Davis and Medina-Ariza 2001; Davis et al. 2001; Navarro et al. 2013). Only one of the studies evaluated the cost-efficiency of the intervention and

discussed potential unanticipated or unintended outcomes (Davis and Medina-Ariza 2001, Davis et al. 2001).

Of the three studies, the strongest evidence for efficacy was found for a public education program combined with home visitation (O'Donnell et al. 2015). The authors concluded that the combination of education and home visits increased the likelihood of reporting elder abuse (Davis and Medina-Ariza 2001, Davis et al. 2001).

14.9 Macrosystem

This system represents the culture within which people live and the values subscribed to by a society, which are operationalized in legislation, policy, heritage and identity. This system had the least amount of studies related to interventions in elder abuse. Five were categorized under descriptive studies, while only one was included under experimental studies.

Within the descriptive studies' papers, two papers discuss legislation in the United States. Connolly (2010) notes that a more facilitative approach to legal redress is needed which includes having a multi-disciplinary advisory team, additional use of forensics and comprehensive evaluation reports. For people in nursing homes, the Patient Protection and Affordable Care Act (US Statute 2010) was considered to enhance care provision in nursing homes in the United States and further safeguard residents (Hawes et al. 2012).

Following court based research with jurors and experts on the financial abuse of older people, Gibson and Greene (2013) argued that the system needed to enable jurors to understand factors unique to such cases, such as the psychological context of the abuse perpetration. It is argued that a using social framework testimony by experts in financial abuse can offer jurors information about the case to help them interpret the evidence in context and without bias, particularly related to potential ageist perceptions. Although the criminal justice route is one standard response for older people who have been abused, the application of a restorative justice framework has been argued as more appropriate, avoiding the adversarial environment of courtrooms (Groh 2005).

While most of the publications focused on the legal system, one paper reports on staffing and finance in detection and intervention services in Japan. Following a survey of 927 municipalities, Nakanishi et al. (2013) noted the need for policymakers to enhance elder abuse staff resources and finances for appropriate services to protect older people.

One intervention was evaluated using an experimental research design was identified as pertaining to the macro-system ecological level (Leedahl and Ferraro 2007). The intervention was an educational program designed to effect change in public attitudes and perception of elder abuse as it is reported in the media (Leedahl and Ferraro 2007). The efficacy of the educational program was evaluated using a randomized controlled trial design with a mixed age sample (N = 60). The authors

found evidence to support the efficacy of education about elder abuse, in the form of reading material, to effect positive change in perceptions of the importance of elder abuse as a topic for media reporting.

14.9.1 Summary

There is a relative paucity of studies which examine interventions in elder abuse at the level of the macro-system. In reviewing the five descriptive studies, many constituted commentaries on process and most referred to the legal response system. While the arguments are valid in terms of process, there is no account of how older people themselves experience the legal system in elder abuse case management and how such data could be used to improve the experience. Despite this, studies point to the need to make the system itself more user-friendly while also addressing any bias in jurors and making the unique features of elder abuse cases transparent. Groh (2005) argues about using a restorative justice approach for elder abuse cases, however, studies cited earlier in this review (Groh and Linden 2011) (Linden 2006) point to the limitations in having restorative justice as an exclusive response system. The Japanese study (Nakanishi et al. 2013) findings point to the fundamental need to have a comprehensive and resourced adult protective service for older people who are abused.

For the experimental study categorized in the macro-system, findings were considered to be undermined by the considerable risk of bias in the design due to the lack of blinding of participants and evaluators (O'Donnell et al. 2015). Furthermore, the quality of the intervention was considered to be weak due to the potential confounders such as the Hawthorn effect, the heterogeneity of a convenience sample, poor outcome measurement and limited explanation of intervention (O'Donnell et al. 2015).

14.10 Discussion

While there are many varying elder abuse interventions in the literature, their transferability may be influenced by structural conditions in different countries. For example, Du Mont et al. (2015) noted that in a review of hospital-based care responses to elder abuse, 4 out of 5 came from the United States or Canada and suggests that applicability within other jurisdictions may be limited.

The review indicated a scarcity of research papers which empirically evaluated interventions targeting the micro-system level, i.e. the older person (n = 5), while there was still a relatively small number categorized under the descriptive studies (n = 13). The majority of the research papers retrieved were in the mesosystem 27, which were descriptive studies and 25 which empirically evaluated interventions using an experimental design; most targeted the relations between micro-system

settings which contain the older person. For the exosystem, there was a disproportionate representation in the descriptive studies (n = 20) as opposed to only 3 interventions for experimental studies. Interventions targeting the macro-system level only accounted for 6 studies; 5 being descriptive and only one focused on an experimental study.

In reviewing the literature related to descriptive studies, it is difficult to evaluate outcomes in papers which provide simple program descriptions without any formal evaluation. In addition, other studies had small sample sizes, which can limit findings. Some interventions could also be demonstrated as having a neutral impact, however, in general, studies acknowledged the need for skilled professionals who have experience in the type of abuse, interagency collaboration and having responses which are acceptable to the older person. Overall the quality of evidence for evaluating the efficacy of interventions described using an experimental research design was poor (O'Donnell et al. 2015). Across the four intervention categories, the highest level of evidence was found to support the exosystem level interventions. While some studies demonstrate success in intervention approaches, there is a paucity of good quality evaluations, in terms of robust design, adequate outcome measurement and clear transferability of the intervention. Evaluating the effectiveness of targeted interventions is challenging due to the complexity of elder abuse and its associated issues, such as self-determination, health challenges, the victim and/or perpetrator dependencies, family and cultural values, lack of standard understandings, as well as structural, policy and legislative gaps.

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Chapter 15
The Public Health Approach to Elder Abuse Prevention in Europe: Progress and Challenges

Yongjie Yon, Janice Lam, Jonathon Passmore, Manfred Huber, and Dinesh Sethi

15.1 Introduction

Abuse and neglect of older adults is a societal problem that exists in all countries (Krug et al. 2002). The World Health Organization (WHO) defines elder abuse as:

> …a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. (WHO 2002 p. 3)

Furthermore, elder abuse can be categorized according to a number of characteristics: type of abuse—psychological, physical, sexual, and financial abuse and neglect; type of abuser—family members, informal and formal caregiver, or acquaintance; and type of settings—community and institution (Gorbien and Eisenstein 2005; Krug et al. 2002; Sethi et al. 2011; WHO 2002).

This book chapter describes the progress and challenges made with addressing elder abuse. It is presented in five sections: (1) Introduction to the problem 2) What is the extent of the problem and has the issue of elder abuse been made more 'visible'; (3) What are the risk factors for elder abuse (4) What works for prevention and are countries implementing prevention programs 5) Are countries developing national action plans to coordinate action against elder abuse?

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15.2 Why Is Elder Abuse So Important?

It was estimated that 5589 older adults aged 60 years and over died by homicide in the WHO European Region in 2016[1] (WHO 2016a). However, deaths only represent the tip of the iceberg because for every death there may be many of hospital admissions and thousands of unreported cases of elder abuse. It is estimated that 15.4% of older adults living in the community and up to 33.4% of older adults residing in the institutions experienced some form of abuse in the past year (Yon et al. 2017, 2018). Elder abuse is both a human rights and a major public health problem due to its serious health consequences for the victims, including the increased risk of morbidity, hospital admission, institutionalization and mortality as well as its negative impact on families and society at large (Lachs et al. 1998; Dong and Wang 2016). Despite its scope and severity, elder abuse remains a largely neglected public health priority in comparison to other types of violence.

By 2030, there will be approximately 250 million adults aged 60 years and over in the WHO European Region (United Nations Department of Economic and Social Affairs 2017). If the rates of elder abuse were to continue, the potential increase in the number of older adults in the community and in institutions who are subjected to abuse and neglect will be enormous. Hence, urgent action is required in the prevention and responses to elder abuse (Sethi et al. 2011).

15.3 Global and European Calls for Action to Prevent Elder Abuse Prevention

To ensure that every older person's right to health and well-being is protected against violence and other forms of adversity, civil societies have called for the establishment of the United Nations (UN) Convention on the Rights of Older Adults to protect and promote the rights of older persons (HelpAge International 2012). By establishing legal standards to address ageist attitudes and behavior, the Convention is expected to enhance accountability of Member States' obligation to older adults (HelpAge International 2012).

The 2030 Agenda for Sustainable Development seeks to realize human rights of all. Ageing is a cross-cutting measure impacted by many of the Sustainable Development Goals (SDGs) where the prevention of elder abuse is included prominently in the SDGs with target 16.1 calling for significant reduction in all forms of violence and related death rates and several more goals focusing on risk factors, including poverty eradication (goal 1), good health (goal 3), gender equality (goal 5), economic growth and decent work (goal 8), reduced inequalities (goal 10), sustainable cities (goal 11), and just and safe communities (goal 16) (UN 2017). The 2030 Agenda emphasizes a life-course approach to ageing while protecting and promoting the rights of older people (UN 2017).

[1] The WHO European Region consists of 53 Member States.

There have been significant global and regional policy developments on elder abuse prevention including a national multi-sectorial approach in the WHO *Global plan of action to strengthen the role of the health* system to address interpersonal violence, in particular against women and girls (WHO 2016b). Furthermore, the WHO *global strategy and action plan on ageing and health* (2016–2020) provides a roadmap to healthy ageing which calls for key actions in the areas of health systems, age-friendly environments, better long-term care as well as improvements in measurement, monitoring and research (WHO 2016c).

Similarly, preventing elder abuse is one of the supporting interventions of the WHO *strategy and action plan for healthy ageing in Europe* (2012–2020). It calls for actions to (1) draw up national policies and plans for preventing elder abuse; (2) improve the evidence base for elder abuse and strengthen capacity for research on effective interventions; (3) build capacity and exchange leading practices across sectors for protection and prevention; (4) raise awareness and target investments on preventing elder abuse; and (5) improve the quality of services in the community and in institutions in order to ensure that quality regulations, standards, protocols and guidelines are in place for preventing elder abuse (WHO 2012).

15.4 The Public Health Approach to Preventing and Responding to Elder Abuse

Successful responses and prevention of elder abuse involve an iterative four-step public health approach (Fig. 15.1). This evidence-informed approach considers the epidemiology and extent of the problem, its risk and protective factors, and the evidence base of what works to develop a model to design, implement, evaluate and monitor interventions and scaling up with a widespread implementation of prevention (Holder et al. 2001). The next sections follow this model.

15.5 What Is the Extent of the Problem and Has Elder Abuse Become More “Visible”?

The foundation of an effective public health response lies in the collection of reliable data. Given the hidden forms of elder abuse, gathering comprehensive data on the problem requires the use of multiple information systems, including vital registration, hospital admissions, and population surveys. At present, routine data collection on elder abuse are limited due to lack of record keeping by health, police, and social service officials.

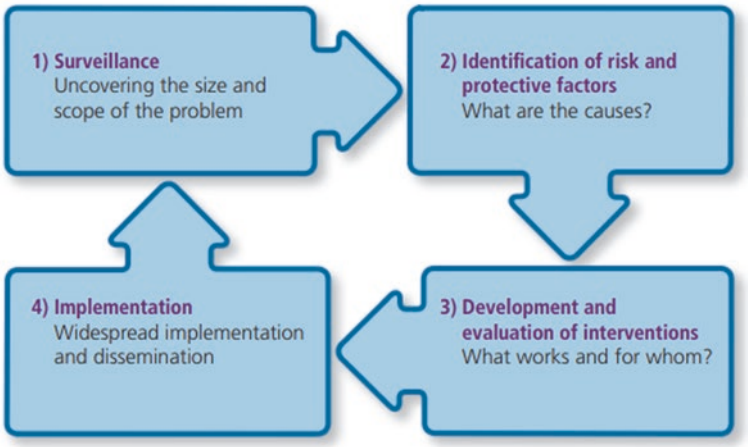

Fig. 15.1 A public health approach to preventing abuse. (Source: WHO 2013)

15.6 Mortality Data for Homicide Among Older Adults

Although there are variations in data quality due to a discrepancy in the coding practices and inaccurate classification of mortality data on assaults and interpersonal violence, nevertheless, vital registration data on mortality are widely available across countries in the Region and may be used as a proxy for deaths from elder abuse, especially in the absence of more direct information. There is a paucity of research in this area, though the *European report on preventing elder maltreatment* estimated that about 30% of these homicide deaths may be attributable to abuse (Sethi et al. 2011). Based on the WHO Global Health Estimates, there were 5589 homicides in older adults aged 60 years and over in 2016, and the proportion of total deaths is higher for men (57.4%) than for women (42.6%), except for older adults aged 70 years and over where there are more women than men due to their longer life expectancies (WHO 2016a). There are gender sub-regional differences in homicide rates in the Region. For instance, homicide rates in males 60 years and over are higher than females: 1.9 times higher in Commonwealth of Independent States (CIS) countries and 1.5 times higher in the European Union (EU) countries.

Data from the European Detailed Mortality Database (Fig. 15.2) highlights a consistent decline in homicide rates since mid-2000s for older adults aged 65 years and over. Trend data from 2004 to 2014 suggest that the homicide mortality rates of older adults in the Region has decreased by 60% (4.55–1.82 per 100,000) over this 10-year period. While this is a welcome success, homicide rates in CIS countries (5.4 per 100,000) are 7.3 times higher than in the EU countries (0.74 per 100,000)

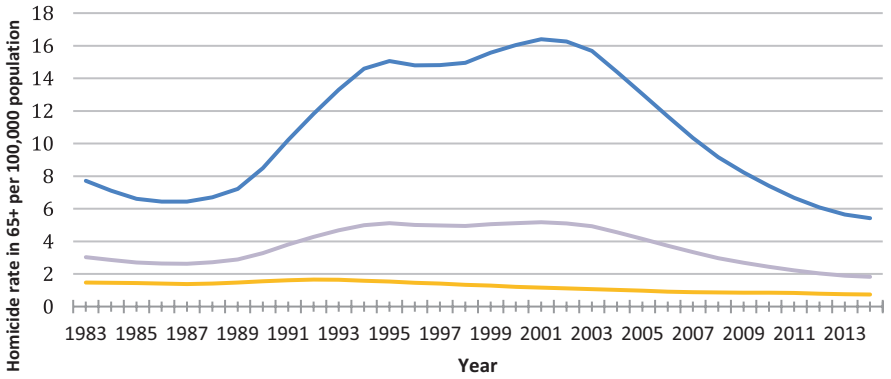

Fig. 15.2 Homicide rate in 65+ years per 100,000 population in the WHO European Region (1983–2014) – 5 year moving average. (Source*:* WHO European Mortality Database 2016d)

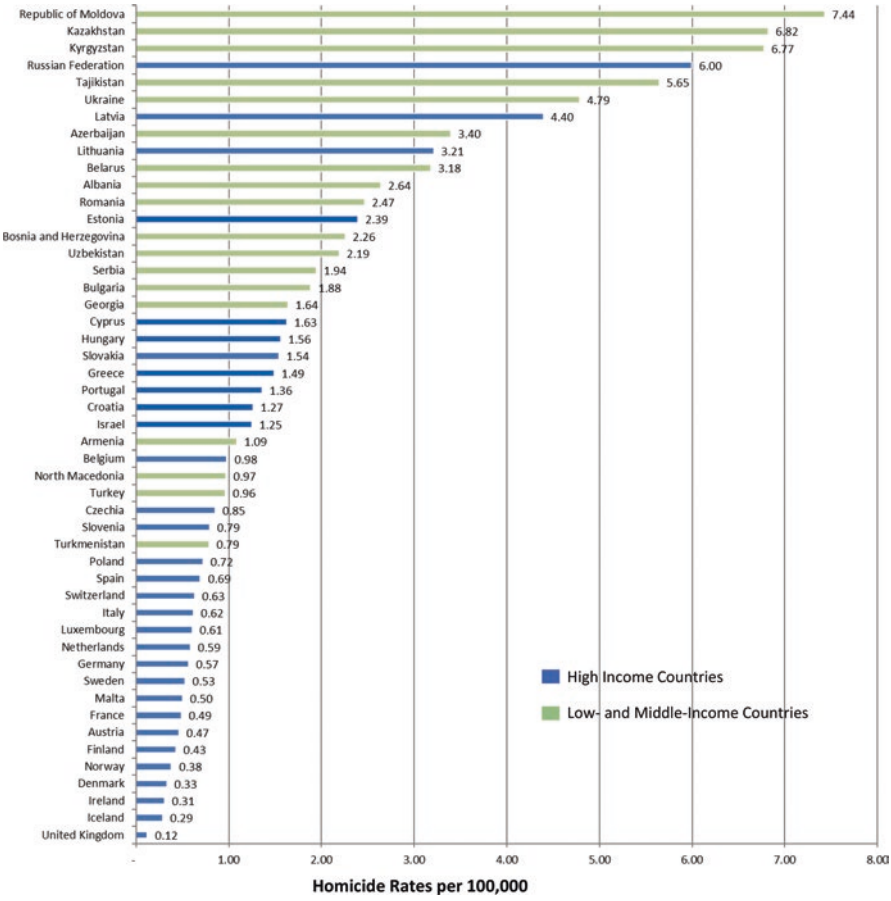

Fig. 15.3 Homicide rates per 100,000 older adults 65+ in the WHO European Region (average for 2012–2016 or last available 5 years). Excluded in the figure are countries with populations less than 200,000 population: Andorra, Monaco, and San Marino. Data was unavailable for Montenegro. (Source: WHO European Mortality Database 2016d)

in 2014 (WHO European Mortality Database 2016d). Nevertheless, the rate of decline in the CIS countries is faster and rates in the Region are converging.

There are large inequalities in homicide rates within the Region. When country-level data are compared using 5-year averages in standardized death rates (SDR) from homicide in 65+ older adults (Fig. 15.3), a 24-fold difference is seen between the country with the highest rate and one of those with the lowest (WHO European Mortality Database 2016d).

15.7 Hospital Admission Data on Assaults Among Older Adults

Hospital admission rates due to assault are a useful source of information to provide additional insight into elder abuse. However, detailed hospital data are not routinely collected or available in a number of countries in the Region. Data disaggregated by age are shown for seven countries with hospital admission data for assaults (ICD-10 codes X85-Y09) (WHO European Mortality Database 2016d). Figure 15.4 shows age-specific hospital admission rate from assaults indicating wide variation by age groups and between countries. In general, admission rates are higher with increasing age. Injuries such as fractures, bruises, head injuries and lacerations can be the result of assaults and falls due through elder abuse (Lachs and Pillemer 2004). The lowest values are reported in Finland and the highest in Czechia. However, results are difficult to compare across countries because of varying clinical practice and in recording and coding procedures. Data quality issues, such as completeness and accuracy of coding of assaults as well as variations in health-system infrastructure and access to services greatly limit cross-country comparability.

15.8 Population Surveys of Elder Abuse

Surveys are an essential component of the public health approach to help understand the true magnitude of elder abuse and its associated risk factors (Sethi et al. 2011). In particular, population surveys currently provide the only method to identify elder abuse that is not captured by vital registration (i.e. homicide data) and hospital admissions (i.e. morbidity data). Survey data can be self-reported from older adults (i.e. victims) or informant (e.g. health professional, in the institutional settings) and is not without its own biases.

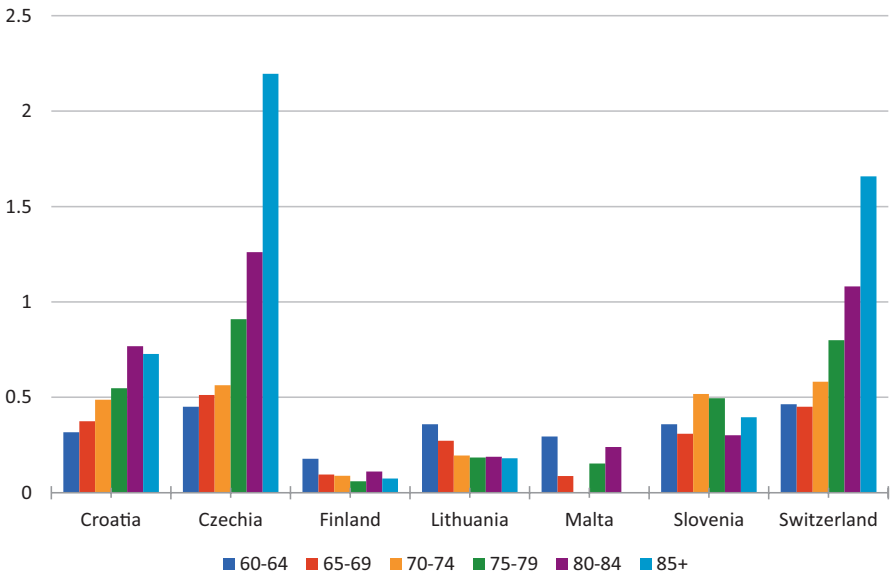

Fig. 15.4 Age-specific hospital admission rates for assaults on elder adults 60+ in select European countries. (Source: WHO European Mortality Database 2016d)

The WHO 2014 *Global status report on violence prevention* described the extent of the problem of interpersonal violence and documented which country are collecting data on violence. The report also assessed the status of program, policy and legislative measures to prevent violence, in its place evaluated the availability of healthcare, social and legal services for victims and identified gaps in interpersonal violence prevention to stimulate national action. Of the 41 out of 53 participating Member States, 40% (n = 16) of countries reported having a national survey to assess elder abuse (WHO 2014a).

In addition, a recent meta-analysis found that one in six older adults (15.4%) experienced elder abuse in community settings in the Region in the past year. Both women and men are as likely to experience abuse (Yon et al. 2017). The lack of gender difference in elder abuse is consistent with research on intimate partner violence and is supported by both systematic review and meta-analysis (Archer 2000, 2002; Anderson 2005). Despite significant awareness of elder abuse in institutional settings, there have been limited studies to examine the prevalence of elder abuse in this setting.

A recent meta-analysis study suggests that rates of abuse are high in institutions (Table 15.1). Results show that staff-to-resident abuse in the past year is as high as 33% in the institution with 3 out of 5 nursing staff admitting to committing some form of abuse in the past year (Yon et al. 2018). Older residents are at highest risk for psychological (33.4%), physical (14.1%), financial (13.8%) abuse, followed by neglect (11.6%), and sexual (1.9%) abuse (Yon et al. 2018).

Table 15.1 Reports of the prevalence of elder abuse in community and institutional settings categorized by type

	Elder abuse in community settings (Yon et al. 2017)	Elder abuse in institutional settings (Yon et al. 2018)	
Type of abuse	Reported by older adults	Reported by older adults and their proxies	Reported by staff
Overall prevalence	15.7%	Not enough data	64.2%
Psychological abuse	11.6%	33.4%	32.5%
Physical abuse	2.6%	14.1%	9.3%
Financial abuse	6.8%	13.8%	Not enough data
Neglect	4.2%	11.6%	12.0%
Sexual abuse	0.9%	1.9%	0.7%

15.9 What Are the Risk and Protective Factors for Elder Abuse?

Abuse and neglect of older adults are a consequence of a complex interaction between many risk and protective factors that operate at the individual, relationship, community and societal levels (Krug et al. 2002). The ecological model is a useful framework to describe these risk and protective factors to promote better understanding and implementation of interventions at the different levels (Schiamberg and Gans 2008; Sethi et al. 2011). At the individual level, strong evidence indicates that having dementia and other disability that creates dependence on carers is a risk factor for being a victim of elder abuse. In the community, perpetration is most often carried out by caregivers who are partners, offspring, or other relatives or carers. For perpetrators, having a history of a mental illness especially depression, a previous history of violence or drug or alcohol dependence are risk factors for perpetrating abuse and neglect of older relatives in their care (Sethi et al. 2011). At the relationship level, risk factors that increase the chances of perpetration includes dependence on the perpetrator, living in the same household, and if the perpetrator is emotionally or financially dependent on the older relative, particularly if due to substance dependence (Pillemer et al. 2016). At the community level, key risk factors include living in isolation without community support networks and where there is ready access to alcohol and drugs. Living in a society where violence is condoned, where there is gender and income inequality and where there is ageism increase the risks of elder abuse at the societal level. For example, living in socioeconomically deprived environments are often associated with a number of risk factors associated with elder abuse such as availability of alcohol and drugs (Dong and Wang 2016). Older people who are living in institutional care are at increased risk when there are inadequate regulatory frameworks and checks, poor staff training, insufficient support of staff, inadequate resources, an ethos that does not put care first, institutions

where violence is tolerated, and if residents are infrequently visited by relatives. Perpetration may be carried out by health and care workers or by visitors (Drennan et al. 2012; McDonald et al. 2012).

Conversely, there are also protective factors which should be encouraged. These include community connectedness and positive life experiences. In care homes, being frequently visited by relatives and friends appears to be protective. The intergenerational effects of previous exposure to violence may also have some impact and needs to be better understood. There is need for greater research to better understand both risk and protective factors (Sethi et al. 2011).

15.10 Are Countries Implementing Prevention Programs?

A public health approach informed by evidence-based interventions is imperative to implement relevant elder abuse prevention programs. Despite limited research on effective interventions for elder abuse prevention compared to other types of domestic violence, a number of promising interventions have been put into place across the Region and elsewhere (Pillemer et al. 2016; Ploeg et al. 2009).

Public and professional information campaigns have been shown to increase awareness of abuse which could lead to early detection and response in addressing elder abuse. In addition, providing support to caregivers has been associated with a reduction in caregiver burden, stress and depression (Pillemer et al. 2016; Ploeg et al. 2009; Fearing et al. 2017). Figure 15.5 highlights the proportion of countries implementing larger scale programs to prevent elder abuse. Of the 41 countries that responded to the *2014 Global status report on violence prevention*, caregiver support programs has been reportedly implemented by half of the countries (51%; n = 21) surveyed; however, public (27%; n = 11) and professional (37%; n = 15) awareness campaigns as well as residential care policies (39%, n = 16) are still not widespread (WHO 2014a, b). Overall, larger-scale implementation of elder abuse prevention programs is more common in EU countries than in the CIS (Fig. 15.6).

Since the adoption of the WHO *strategy and action plan for healthy ageing in Europe* (2012–2020) WHO Europe is conducting a preliminary review to assess the degree of development and implementation of policies including supporting interventions associated with elder abuse prevention. To assess the progress, a review was conducted on the national progress reports on policies for ageing societies submitted to the United Economic Commission for Europe (UNECE 2017). A total of 44 reports from Member States were submitted as part of the third cycle of the implementation of the Madrid International Plan of Action on Ageing Regional Implementation Strategy. Of these reports, 42 fall within the WHO European region and 41 reports were assessed and analyzed. Activities on elder abuse prevention were described in the majority of the reports (63%; n = 26). While findings from this review are preliminary, the results suggest that the public and policy-makers are increasingly concerned about the problem.

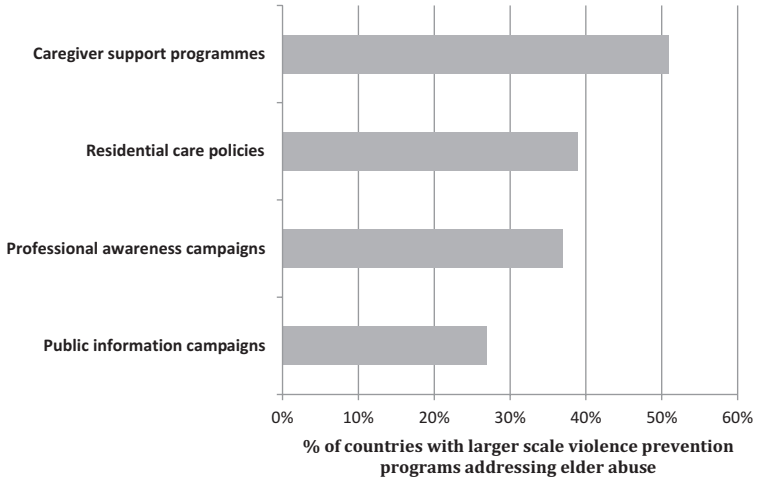

Fig. 15.5 Proportion of countries in the WHO European Region implementing violence-prevention programs on a larger scale to address elder abuse. (Source: WHO 2014b)

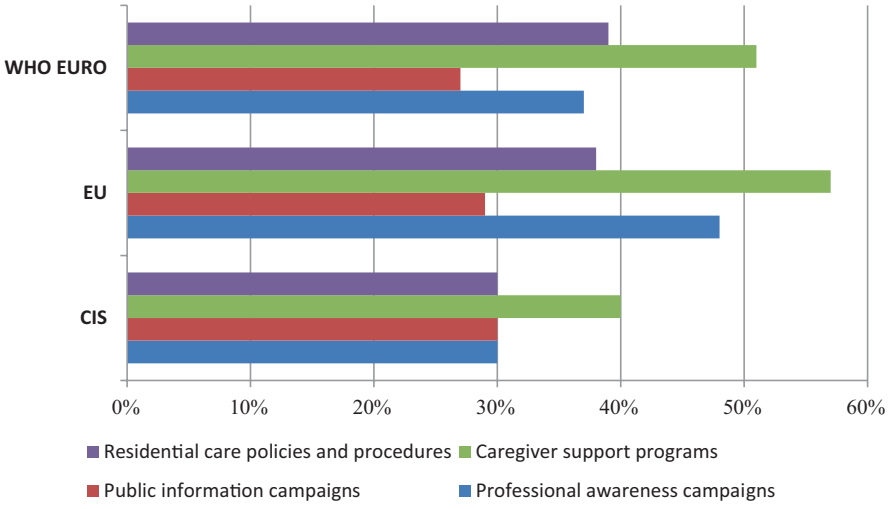

Fig. 15.6 Large scale elder abuse prevention programs in the WHO European region and sub-regions (% of countries). (Source: WHO 2014b)

The provision of health and social services are essential for the prevention, detection and response to elder abuse (WHO 2016e). Hence, strengthening the health and welfare systems and service provision for person-centered care can help reduce the recurrence of elder abuse, prevent new cases, and improve physical and mental health outcomes. The 2014 *Global status report on violence prevention* also assessed

and evaluated the availability of health, social and legal services for the victims of violence, including elder abuse (WHO 2014a). A sensitive response to the detection of elder abuse is important to prevent further harm to the victims. For the Region, adult protective services have not been implemented on a large scale which indicates that the cases of abuse among older adults may remain hidden from adult protective services. About 66% (n = 27) of the countries have adult protective services across the Region, however, only 41% (n = 17) of the countries have implemented these systematically on a large scale (WHO 2014b).

While there are many risk factors that lead to increased risk for sexual violence and intimate partner abuse (Ramsey-Klawsnik 1991, 2004), health systems play a crucial role in the multi-sectorial response to provide access to quality, comprehensive services for survivors. Although it is unclear whether specialized services are indeed available for older adults that are sensitive to their needs, nevertheless, about 85% (n = 35) of the countries have services for victims of intimate partner and sexual violence provided by health care providers across the Region and about 60% (n = 24) have implemented the services on a large scale. The provision of medico-legal services is important for victims of sexual violence to ensure their protection. Health-care providers should be trained to ensure they have a good understanding of their country's jurisdictions in reporting and responding to cases of sexual abuse. Almost all of the countries (98%, n = 40) in the Region have medico-legal services for victims; 73% (n = 30) of countries have it systematically on a large scale. Income-level inequalities between countries in the Region exist for implementing medico-legal services for the victims, with 76% (n = 19) of High Income Countries (HICs) and 69% (n = 11) of Low- and Middle- Income Countries (LMICs) reporting provision of these services on a large scale (WHO 2014b).

Poor mental health and psychiatric illnesses are both a risk factor and consequence of elder abuse (Cooper and Livingston 2014). Mental health services for victims of violence in all age groups exist in 92% (n = 38) of countries in the Region; 66% (n = 27) have implemented them systematically on a large scale. There is a large inequality in the provision of mental health services for victims of violence. By income grouping, 72% (n = 18) of HICs and 56% (n = 9) of LMICs have mental health services implemented on a large scale (WHO 2014b).

15.11 Are Countries Developing National Action Plans to Coordinate Action Against Elder Abuse?

The key message to policy-makers and members of civil society is that elder abuse is wide-spread but not inevitable and can be prevented by taking a multi-sectorial and public health approach. Developing an action plan is an important step toward effective and coordinated approach to elder abuse prevention. In particular, an action plan defines a framework for a comprehensive, systematic, multi-sectorial and multidisciplinary approach to prevention at all levels – local, regional, national and international (Schopper et al. 2006).

Findings from the *2014 Global status report on violence prevention* indicates that 53% (n = 22) of countries in the Region have a national or subnational action plan for elder abuse prevention (WHO 2014a, b). However, to establish realistic action plans with specific quantified targets, timelines and monitoring strategies as well as good epidemiological data are needed. Of the countries that have developed an action plan for elder abuse prevention, over 45% have survey data (WHO 2014a, b). In other words, the majority of the actions in countries to date have not been informed by survey data. It is important that countries strengthen the collection of good epidemiological data to inform the development of realistic national prevention action plans and set quantified targets and timelines to monitor implementation (WHO 2014b).

Overall, country investment in violence prevention does not appear to match the magnitude of the problem of elder abuse. Compared to the case of a specific action plan on elder abuse prevention, there have been greater country investments in other action plans in the Region: child maltreatment (78%), youth violence (63%), interpersonal violence (51%), intimate-partner violence (85%), and sexual violence (76%). While some of these action plans may be related to violence against older adults, there remains a lack of specific attention and investment to elder abuse prevention. Given the complexity and cross-sectorial nature of preventing and responding to elder abuse, a regular information exchange is needed to access, oversee and coordinate prevention activities (Lachs and Pillemer 2004; Navarro et al. 2010). In addition, responding to the complex cases of elder abuse involves a multidisciplinary team that utilizes different sectors and disciplines to investigate, referral and resolve cases. Yet, health and social services are often fragmented and underfunded. Multidisciplinary teams have been identified as an important best practice in responding to elder abuse (Wolf and Pillemer 1994) and research indicated that having access to professionals and experts in social services, criminal justice, and health care fields can lead to increased criminal prosecution as well as access to victim services (Navarro et al. 2013). Currently, only 78% (n = 32) of countries surveyed have an information exchange system in place, but the comprehensiveness of its coverage across all age segments is unclear (WHO 2014b).

Given the devastating impact of elder abuse, protecting older adults from abuse and neglect is considered a core function of governance for public health. In addition to action plans, governments have an important role to enact and enforce legislation to prevent elder abuse and protect the rights of older adults. Results from the 2014 *Global status report on violence prevention* found that 90% of 41 reporting countries in the Region have laws relevant to violence; however, only 71% (n = 29) are directly related to addressing elder abuse and 59% (n = 24) relating to addressing elder abuse in institutions. Enforcing laws to prevent elder abuse is also inadequate as only 41% (n = 17) of countries reported enforcing laws to prevent elder abuse in community settings and 29% (n = 12) in institutional settings (WHO 2014b). Overall, this level of reporting is inadequate which undermines the protection and promotion of the rights of older people. This is especially true with 32% of HICs compared to 25% of LMICs in enforcing legislation against elder abuse in the institutional settings.

15.12 Conclusion: The Way Forward

Preventing elder abuse in Europe requires a stronger policy response and meaningful resources to address this growing public health priority. Elder abuse has not received the attention it should have, and only half the countries report having national action plans. Moreover, over half of elder abuse prevention action plans were developed without being informed by a population-based survey. Fewer countries report laws to prevent elder abuse in community and/or institutional settings than for other areas of violence prevention. Such fragmentation is not surprising since violence prevention activities including elder abuse are often spread across multiple agencies, often without a lead agency identified for accountability and monitoring purposes (WHO 2014b). Policies and national action plans for the prevention of elder abuse need to be given at least as much attention as other types of domestic violence where over 90% of countries have action plans.

A number of countries are investing in prevention, but not at a level commensurate to the scale and severity of the problem. As such, a series of integrated actions in accordance with international directives, adopted by Member States need to be undertaken. Governments, municipal authorities, international agencies, Non Governmental Organizations, practitioners, and other stakeholders need to address the social injustice and inequity caused by the abuse and neglect of older people. They need to consider the following actions:

1. Develop and implement national policies and plans for preventing elder abuse.
2. Take action to improve data on and surveillance of elder abuse.
3. Evaluative research on prevention programming needs to be undertaken as a priority.
4. Response for victims need to be strengthened.
5. Address inequity by strengthening the prevention and response to elder abuse.
6. Build capacity across the sectors and promote intersectoral collaboration.
7. Raise awareness and target investment for preventing elder abuse.
8. Invest in protective factors across the life-course approach to promote intergenerational cohesion.
9. Enhance governance structures to improve the ethical standards and quality of services in the community and in institutions.

This chapter highlights the public health problem of elder abuse and its likelihood to increase given the rapidly ageing population in the European Region. It advocates a public health approach to this problem, which is likely to grow unless urgent action is taken. Even though homicides rates among older adults have declined by 60% between 2004 and 2014, population-based surveys show that the prevalence of abuse in the community and in institutions remains high. Overall, this neglected public health priority requires countries to significantly improve their policy and programmatic response which has been inadequate to date.

The views expressed by authors and editors do not necessarily represent the decisions or the stated policy of the World Health Organization.

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Chapter 16
Human Rights and Elder Abuse: The Case Example of Serbia

Natasa Todorovic and Milutin Vracevic

Elder abuse is a complex problem cross-cutting through social sphere, public health and other distinct areas and it is a violation of human rights. The effects of elder abuse can be dramatic not just for the older person experiencing abuse and her or his immediate surroundings but also for society at large.

The phenomenon of demographic ageing has over the past 20 years highlighted the severity and seriousness of elder abuse, a problem that has for decades been quietly overlooked (Krug et al. 2002). Despite the attention that it has now garnered, elder abuse demands additional efforts in at least three different directions: further research into the phenomenon as to better understand its scope as well as its different aspects, raising public awareness on the phenomenon, as well as better prevention and better regulatory frameworks. Based on these three directions, the Red Cross of Serbia's engagement with the phenomenon of elder abuse has also been developed in three distinct branches.

16.1 Background Situation in Serbia

The data and the estimations of the Statistical Office of the Republic of Serbia for 2016 put the Serbian population at 7,058,322 whereas people over 65 years comprised 19% of the total population. In the population over 65 years, 57.5% were female in 2016. With median age of 42.88 years and the ageing index of 139.5, the Serbian population is one of the oldest in the world. Additionally, the population growth quotient was calculated at −5.3% for 2017, demonstrating the continuing trend of depopulation in Serbia (Statistical Office of the Republic of Serbia 2017).

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For male children born in the 2014–2016 period, life expectancy was 73.01 years and 77.98 years for female children born in the same period (Statistical Office of the Republic of Serbia 2017). The longer life expectancy for women has its drawbacks as it may lead to more years spent in worsened health. Also due to gender inequalities during the active years, women are often faced with less favorable material status in their older age and thus more likely to experience poverty. The statistics show that in the over 65 years population, the risk of poverty is significantly higher for women than for men (22% vs. 15.2%) (Babovic et al. 2018).

According to the projections by the Statistical Office of the Republic of Serbia, older people's proportion in the total population will continue to grow, especially women over 80 years and by 2041 the proportion of persons older than 65 years is expected to increase from 17% to 24%, while the rate of dependency of older people during the projection period is expected to increase from 25% to 39% (Statistical Office of the Republic of Serbia 2017).

16.2 Data and Research

When the Red Cross in Serbia started engaging with this problem some 15 years ago, there was only one available Serbian study on elder abuse. Consequently, it was clear that more research was needed to establish the prevalence of this phenomenon in Serbia. In addition, it was important to explore the regulatory and institutional framework in Serbia, examine existing policies and mechanisms to prevent and respond to elder abuse and establish to what extent the system is effective in protecting the human rights of older people.

According to the data published by the Republic Institute for Social Protection and collected through the network of Centres for Social Welfare in 2016, the number of reported cases of domestic violence and intimate partner violence was 23,218. Out of this number, 3018 were reported cases of elder abuse in family context, representing a 13% share. This is a noticeable increase in the number of reported cases of domestic violence in comparison with data from 2010 where the total number of reported cases was 8481 and the number of elder abuse cases was 1056–12.45% of all reported cases (Republicki Zavod za Socijalnu Zastitu 2017a, b, c; Republicki Zavod za Socijalnu Zastitu 2011).

Despite the increase in the number of reported cases of domestic abuse and elder domestic abuse among them, this is still a small number in comparison with the prevalence of elder abuse in Serbia established through research and which is in line with the data from other European Countries as well as global data. This fits the pattern of elder abuse being substantially underreported (World Health Organization 2008).

The Red Cross of Serbia has undertaken three research studies on elder abuse and two other studies that have focused on older people in Serbia. The first elder abuse study, 'Elder abuse: a study of violence in family context' (Petrusic et al. 2012) is based on research of the legal framework and challenges related to reporting

abuse, processing the data related to these cases and managing the cases themselves. The second study 'Introduction to ageing and human rights of older people in Serbia' (Petrusic et al. 2015) is a pilot research study on financial elder abuse, the first of its kind done in Serbia. The third study, 'Well-kept family secret: elder abuse' (Jankovic et al. 2015) has looked into prevalence of elder abuse in Serbia.

'Elder abuse: a study of violence in family context', published (Petrusic et al. 2012) in February 2012, had two parts. The report provided an overview of the existing legal framework in Serbia related to protection from violence in family context. In addition, this report analysed selected cases of elder abuse targeting multiple persons. Findings identified key problems in the management of elder abuse by public institutions related to the provision of psychosocial support and legal protection to older persons experiencing abuse, assessing whether cooperation and coordination between different public institutions has existed and to what extent such collaboration was effective.

The study analysed the data on violence in the family context provided by Centres for Social Welfare and police administration from the second and third largest cities in Serbia, Nis and Novi Sad. Elder abuse cases were selected from those reported in these two cities and the analysis looked at how many older people were targeted, where the abuse and violence took place, who the perpetrators were, what was the method of collecting the data on the case as well as examining how much and in what ways the institutions cooperated and coordinated their work related to the cases.

Among the processed cases of family violence, approximately 10% targeted older family members. More than 75% of older persons experiencing violence in their families were female. The average age of the older person experiencing violence in the family context was over 70 years. As for the perpetrators, the vast majority (more than 90%) were male and most frequently children or grandchildren of the victims (Petrusic et al. 2012).

When considering the catalyst to the case being reported to public institutions, physical violence was identified as the most common reason whereas psychological violence was rarely formally reported. It could be argued that the tolerance threshold for psychological violence is very high for older persons and that this form of violence is not considered to be substantial enough to generate a formal report to services. This suggests that psychological violence needs to be defined precisely, in order for it to be better identified. Psychological violence most frequently takes the form of threats of physical harm, including threats to kill as well as verbal abuse.

In reviewing cases, a number of problems were identified in the case management which include the following:

- There is no established and unified way and form through which to regularly and systematically record, document and process cases of violence in family context that would ensure collection of data related to perpetrators and victims of violence, the characteristics of violence, the reaction of public institutions, the introduced measures to support the victims and punish the perpetrators etc.

- There is no regular practice of exchanging information between relevant public institutions and organisations on violence in family context, including the violence against older persons, which particularly minimises the capacity of persons surviving violence to exercise their right to efficient and effective protection from violence.
- It is not established who should be responsible for the case management and what the procedure should be to ensure that older people targeted by violence in family context obtain a free of charge medical certificate based on medical or forensic medicine examination, as well as adequate healthcare, including psychological support and therapy when needed. This certificate establishes the case and contains relevant evidence that can be used in the court of law
- There are no specific services of social welfare developed for older persons who have survived violence in family context; this would include therapy and rehabilitation in line with their needs and living circumstances.
- There is no provision for older people surviving violence in the family context to receive good quality, professional legal assistance, either free of charge or at subsidised prices (Petrusic et al. 2012).

Based on the results of the study, recommendations were provided to improve the Serbian legal framework, as well as the way cases of elder abuse were managed. Services providing protection and support to older people are not well coordinated and are fragmented and scattered in different public departments (police, judiciary, health institutions, centers for social welfare) that do not communicate and share information with each other in ways that would ensure adequate protection.

A recommendation on how to improve the legal framework suggests that the Criminal Law of the Republic of Serbia explicitly recognises violence against an older person in family context as a distinct act and aggravating factor. Such a change would ensure a deterrent to abuse perpetration and provide adequate punishment of violent acts targeting older family members who represent a distinct and vulnerable group in the society.

The second research study by the Red Cross of Serbia on violence targeting older people was published in November 2015, entitled ‘Introduction to Ageing and Human Rights of Older People: Pilot Research Study on Financial Abuse of Older People’ This is the first study in Serbia looking into the concept of human rights of older people which included a focus on financial abuse.

The first part of this study explores the concept of human rights. The second part is an overview of international, regional (EU) and national legislative frameworks related to the protection of human rights of older people and anti-discrimination regulations. Special attention was given to national legislation related to livelihood and inheritance. The third part of this report presents the results of an exploratory study of financial abuse of older people and case studies related to deprivation of the legal capacity of older people and the issues arising around life care contracts.

Designed as pilot study, the field research involved interviews with 140 randomly chosen persons over 65 years of age who resided in ten different municipalities

in Serbia. Due to the size and characteristics of the sample, the results of the study are not to be taken as representative in and of themselves, but serve the purpose of providing useful findings to develop hypotheses for future research that will have broader scope.

In the sample, 69% of the participants were female and 31% were male. Sixty nine percent of the sample lived in urban areas, 19% lived in rural areas and 12% lived in peri-urban areas (Petrusic et al. 2015).

To assess the risk of financial abuse, the researchers asked 'Is someone authorised to manage your bank account?' Almost 40% of the participants responded with "yes". Eight percent of the older people stated that someone was using their money without their knowledge (Petrusic et al. 2015).

One hypothesis arising from the results of this study was that there is a marked presence of strong patriarchy in family relations in Serbia that is characterised by a model of parental self-sacrifice for their children. This characteristic increases the risk of financial abuse but at the same time makes it more difficult to identify it, due to the protective instinct towards the child of the parent(s). To further probe this concept, a question was asked: 'If you won a lottery, what would you spend the money on?' More than 50% of the participants said they would pass the winnings on to their children or grandchildren while only 9% would use it to travel and 7.1% would use it to go to a spa (Petrusic et al. 2015).

Further reinforcing the hypothesis of patriarchal relations and existing characteristics of self-sacrifice are the expectations of the child inheriting property after the passing of marital partner (Petrusic et al. 2015). Services providing protection and support to older people are not well coordinated and are fragmented and scattered in different public departments (police, judiciary, health institutions, centers for social welfare) that do not communicate and share information with each other in ways that would ensure adequate protection.

Looking to gain a deeper and more comprehensive insight into the phenomenon, we used a case study method. We analysed two scenarios: one was where a person was being declared legally incompetent and deprived of legal capacity, and the other was where there was of termination of a lifelong care contract that was initiated by the older person. Life support contracts are regulated by the Law on Inheritance and they stipulate exchange of property for lifelong service.

The case studies showed that despite the law requiring that the legal petition to deprive a person of their legal capacity must present the facts on which it is based as well as evidence that establishes these facts as true or believable, in some of the cases analysed the reasons quoted in the petition were illogical and have not demonstrated that the person was incapable of taking care of her/himself, indicating possible ageist prejudice.

A second observation is related to the legal obligation of the court to interview the person to establish the facts and to identify if legal capacity is diminished or present. However, this criteria may be sidestepped if it is assumed that the interview could negatively affect the person's health or if the mental status of the person does not support the conduct of an interview. In the five cases examined in this report, it was observed that the court had not interviewed the persons undergoing the legal

competency assessment. Having in mind that this is a small number of cases, generalisations should not be made but still this does indicate risks to human rights of older people in terms of being rendered silent and having their rights deprived in such procedures in Serbia.

As for the scenarios related to termination of life care contracts, six such cases were studied. Lifelong support contracts are regulated by the Law on Inheritance and they stipulate exchange of property for lifelong service. It is legally stipulated that the contract must be written and signed in front of a judge. The judge is legally obliged to inform the older person that the property described in the contract will not upon her or his passing be part of the inheritance. This was a particular point of interest in the research as it was noticed that despite the law granting the option to dissolve the contract if unsatisfied with the services, many older people will not reconsider the arrangement, even if this is clearly to their benefit. What scares older people off is the potential of high court expenses and the risk of being ordered to reimburse the services already received up to that point. Older people are therefore often apprehensive of entering such contracts – even though they could ensure basic quality of life in their older age – because the prevalence of suspicious contracts seems to be relatively high.

This report made recommendations which include improving the legal framework through amending the Family Law to address issues such as ensuring the older person's continued self determination in financial matters or where their best interests are central to financial decision making if incapacity is present.

As for legal capacity, full deprivation of a person of their legal capacity is unacceptable from the perspective of human rights (Fredvang and Biggs 2012) and the recommendations include changing the legislation as to reflect this concern but also to work with the courts to minimise prejudices towards older age and dementia in order to ensure that human rights of older people are fully protected.

This study has given initial insights into human rights and financial abuse of older people in Serbia, however, it also demonstrates that broader and more in depth research is necessary, with a special focus on different fraudulent practices such as telemarketing frauds. Considering there is not adequate protection for older people in the context of financial abuse, it is necessary to use broad, inter-sectorial approach in addressing such issues, including working with banks.

When such elder financial abuse takes place, older people usually find legal remedies costly, time consuming and out of their reach, among other things due to potential additional costs, but also due to the feeling of shame for raising concerns about their family. However, it is also imperative to recognise that often older people do not fully comprehend or even recognise that they are being abused.

All of the data collected served to create a Serbian based body of knowledge on the phenomenon that was almost completely overlooked in the past. In addition, the data collected provided us with basis for our other activities: increasing public awareness on the phenomenon of elder abuse and its prevalence as well as providing platforms for public advocacy activities ranging from changing the legislation to challenging ageist stereotypes that are among major contributors to the different

forms of elder abuse (Krug et al. 2002; Nelson 2005) (See Taylor in this book for advocacy).

The third study undertaken by the Red Cross of Serbia into elder abuse was undertaken in 2015 in cooperation with the office of Commissioner for Protection of Equality. The results were published in a report entitled 'Well-kept family secret: elder abuse' (Jankovic, Todorovic, Vracevic 2015). The research involved telephone interviewing with a sample of 800 people over the age of 65 years (average age of the interviewee: 73). Findings demonstrated that 19.8% of the population over the age of 65 years in Serbia have been exposed to some form of abuse in their older age, with 11% reporting the abuse took place over the last 12 months. The highest risk was of financial abuse, with 11.5% of the population being exposed to some form of financial abuse with theft being the most frequently experienced type. More than thirteen percent (13.5%) of the interviewees stated that they do not have complete control of how they use their finances, indicating the high risk of financial abuse. Fifty four percent of the interviewees have reported using their income to support other members of the household they live in. However, older people frequently do not perceive this as financial abuse, including situations where they are not in full control of their finances. For some older people, they reason that they are old and do not need the money that younger family members may be in more need of.

Furthermore, 3.9% of older people reported physical abuse, with 2% experiencing it in the last 12 months and 0.7% being targeted three or more times in the last year. Almost eight percent (7.8%) reported psychological/verbal/emotional abuse; 4.6% in the last 12 months, with 2.5% experiencing it three or more times in the last year. In 1.4% of the reports, the perpetrator of this form of abuse was a family member and in 3% of the cases it was reported as other people (Jankovic et al. 2015). Fifty percent of the interviewed older people declined to answer the questions related to sexual abuse. This may be due to a reticence to discuss sexual abuse due to its taboo nature. Only one interviewee reported that they were target of an attempt of sexual contact by a third party.

Neglect was reported by 3.4% of older people and this percentage was higher (5.1%) for those who need assistance with daily activities than for those who need no such assistance (2.2%) (Jankovic et al. 2015). This agrees with other international studies on risk factors for elder abuse (Pillemer et al. 2016).

In total, 19.8% of older people experienced some form of abuse or neglect with 5.5% reported experiencing multiple forms of abuse. Eleven percent experienced some form of abuse over the 12 months preceding the interview (Jankovic et al. 2015).

In a separate research study on older people living in rural areas in Serbia undertaken in 2016 (Jankovic et al. 2016), 9% of the interviewed older people reported having experienced some form of elder abuse or neglect. Nevertheless, 'Well-kept family secret: elder abuse' is the largest research study on elder abuse done in Serbia. The data on elder abuse in Serbia is quite similar to the data from global and

regional sources in terms of overall prevalence and prevalence of different forms of abuse (Yon et al. 2017). However, the need for new and additional research into this phenomenon and its different aspects is still very important especially considering some slight variation from data presented by studies from European countries (Pillemer et al. 2016).

The two most recent research studies undertaken by the Red Cross of Serbia, 'Older People in Rural Areas' (2016) and "Ageing in Cities" (2018) have not dealt with elder abuse directly, but have looked into how older people perceive and experience age-based discrimination. Both studies provided insight into obstacles older Serbian people have in exercising some of their guaranteed rights (health, social protection). Such insights are important as age-based discrimination can be treated as a society-level risk factor for elder abuse (see Chap. 2 by Phelan and Ayalon).

In rural areas in Serbia, 27% of the participants reported having personally experienced age-based discrimination (Jankovic et al. 2016). The urban areas of Serbia had a higher figure, with 33% of participants reported age discrimination (Jankovic et al. 2018). This contrasts with other age groups as it is a significantly higher than among than in the general population where 13% report having been discriminated against on any basis (Poverenik za zastitu ravnopravnosti 2017). These findings point to the fact that older people appear to be at a higher risk of discrimination than general population.

16.3 Awareness Raising

Through our awareness raising activities, the Red Cross try to raise public and political understandings and recognition of elder abuse, its scope, complexity and consequences, particularly from a rights based perspective. The Red Cross of Serbia has marked World Elder Abuse Awareness Day (WEAAD)– 15 June – every year since 2007, starting 1 year after the date was established. In the early years, WEAAD was the main vehicle for awareness raising, ensuring good media coverage that was initially peaking around June but in later years spread to the rest of the year. Elder abuse was practically completely absent from the media and overlooked in the public sphere in Serbia in the past. The Red Cross have also organised awareness raising through advertising campaigns in public transportation vehicles in several cities in Serbia and a targeted billboard campaign.

Other initiatives to mark WEAAD include the organisation of panel discussions between professionals working in the fields of health, social work, public service etc., which focused on the common topics of ageing and elder abuse. In addition to the media, these meetings also featured practitioners from public institutions and representatives of organisations not working directly with ageing but interested in human rights from different aspects (e.g. women's organisations, organisations of persons with disabilities) which created a ripple effect of many different stakeholders starting to independently address the problem of elder abuse. Furthermore, this contributed to the public institutions taking an interest in the topic and engaging with the

issue in a more comprehensive fashion. Additional activity to mark the 15 June includes regular visits to policy makers by delegations of older people as part of the global Age Demands Action campaign coordinated by HelpAge International. These activities have also resulted in the Red Cross establishing partnerships with human rights institutions such as the national Ombudsman and Commissioner for Protection of Equality and this had increased the focus on elder abuse in these institutions.

16.4 Advocacy

All the evidence and data collection as well as awareness raising activities cited above are intertwined with advocacy aiming to improve protection of older people and prevention of elder abuse. In advocacy, the Red Cross generally works on three levels: local, national and international.

At a local level, there are networks of Red Cross branches and partnerships with local grassroots civil society organisations and initiatives. The Red Cross have developed a one-day workshop curriculum for older people on their human rights with a large portion of it devoted to abuse and protection from abuse, so through the network of organisations and initiatives, older people are informed about their human rights and the ways to access and protect them. This curriculum was shared with partners in the region: Albania, Bosnia and Herzegovina, Macedonia and Montenegro. In 2016, the Red Cross supported the development of civil society advocacy networks in Macedonia and Montenegro. At the same time, the authors have worked with the Red Cross of Serbia branches to ensure that they are equipped to provide older people who are suspected of being abused with support ranging from psychosocial support to assistance with accessing local public institutions and exercising their rights.

At national level, the Red Cross of Serbia is a founding member and coordinator of a civil society organisations advocacy network HumanaS. The network advocates for improved protection of human rights of older people and one of its main focuses is the issue of elder abuse. In 2018, the network had 17 member organisations. Initiatives of the network are aimed at policy makers to influence changes in legislation so that elder abuse is defined as a distinct act of violence by law. Additionally, the Red Cross works with policy makers at national level to try to contribute to improving coordination between local level public institutions and services in cases of elder abuse, including the way the records on these cases are maintained and data shared between institutions and services. This should lead to making it easier for older people experiencing elder abuse to report the abuse, going through a well-designed procedure that minimises additional stress and secondary victimisation.

When it comes to elder abuse as a violation of human rights, at international level the Red Cross of Serbia works in partnership with different organisations. The Red Cross are affiliate members of HelpAge International network, represent International Network for Prevention of Elder Abuse (INPEA), are members of Global Alliance for the Rights of Older People (GAROP) and are participating in the process of creating the New United Nations (UN) Convention on the Rights of

Older People. The Red Cross also participated in the work of United Nations Department of Economic and Social Affairs (UN DESA) Expert Group Meeting on the Violence Against and Abuse of Older Women (2013) as well as participating in the fifth session of the Open-Ended Working Group on Ageing in the UN at a panel, talking about financial abuse of older women (2014).

In the process of advocating for the New UN Convention, the Red Cross have had several meetings with the Ministry of Foreign Affairs of the republic of Serbia, to discuss the participation of Serbian representatives in the work of the Open-Ended Working group on Ageing. An older female volunteer of the Red Cross of Serbia has, with support by HelpAge International, participated in the eighth session of the Open-Ended Working Group on Ageing that focused on discrimination and abuse. The Red Cross is also a regular participant in the meetings of the Working Group on Ageing organised in the Geneva UN headquarters every year.

All these international advocacy activities are important not only in and of themselves, but also in the national context where experiences from the global level are adapted for use in advocacy at national level.

Another part of the work of the Serbian Red Cross is with the International Red Cross Red Crescent movement, where our organisation is spearheading the idea that the movement should be more focused on protecting the human rights of older people and more active in finding the ways to support older people affected by or at risk of elder abuse.

16.5 Way Forward

The Serbian Red Cross plans for the future include work on several different levels. One focus includes a plan to undertake a larger scale study, using a representative sample, on the prevalence of elder abuse in Serbia. A second objective is to undertake a prevalence study of elder abuse in residential care of older people in Serbia. The only related research study, to date, has been undertaken by a partner civil society organisation, Amity (Sataric et al. 2018). This study had a very small sample (75 older women in residential care) and focused on the access to human rights in residential care institutions in Serbia. Findings demonstrated that 52% of the participants did not make autonomous decision to move into residential care – they were either pressured into accepting the decision or they were not even consulted about it. The data related to abuse within the institution is very inconclusive though, with none of the participants reporting experiencing abuse since moving into the institution (Sataric et al. 2018).

Reported cases of violence against older people in institutions collected by the Institute for Social Protection from both private and public residential care institutions in 2016 show that the overwhelming majority of cases – 72 out of 74 – report abuse perpetrated by another resident and only two report the abuse was perpetrated by a staff member. The majority of victims were female and the most prevalent form of abuse reported was physical abuse (Republicki zavod za socijalnu zastitu 2017a).

Out of all recorded cases, private institutions account for 14 cases and none of these cases involve a staff member (Republicki zavod za socijalnu zastitu 2017b). This suggests that additional studies on this topic are needed to shed light on the issue of elder abuse in residential care institutions as well as increasing such care environments' sensitivity to the phenomenon. Despite the fact that the number of studies across the globe related to abuse in residential care is not high (Yon et al. 2018), prevalence data from those studies still suggests that the numbers for Serbia seem to be disproportionally low, especially in relation to abuse perpetrated by staff of residential care institutions (Yon et al. 2018; World Health Organization 2018). This last issue is particularly important considering that residential care institutions – especially private ones – have been mushrooming all over the country in the past several years.

Other plans include the Red Cross, establishing cooperation with organisations focusing on other societal groups at risk of abuse, such as women, people with disabilities, ethnic and sexual orientation minorities. This will assist a general awareness of abuse and neglect of all individuals and the duty to ensure equal enjoyment of human rights.

As a dominant service provider to care of older people, the Red Cross also plans to focus on deeper cooperation with the health sector, so that more attention is paid to elder abuse among health professionals. Here, focus will first be on general practitioners because they are the first line of professionals encountering potential victims of abuse and need to provide medical evidence of abuse occurring should the court case be established.

Finally, the Red Cross recognised that more work should be done on prevention of abuse through providing support to both formal and informal carers and establishing support services for older people who are either survivors of elder abuse or are identified to be at a high risk.

16.6 Conclusion

The Red Cross has undertaken a number of activities in Serbia to address elder abuse. This includes the generation of local data on elder abuse, awareness raising, advocacy and national and international activities. For the future, the Red Cross will also continue engaging in regular advocacy activities related to elder abuse, focusing on improving legal frameworks, better implementation of existing legislation, using the rights-based approach and promoting the concept of human rights of older people.

Reflecting on the work completed in relation to elder abuse, the are three important synergies to be nurtured: by being engaged in research as well as advocacy at the same time, the Red Cross gained an edge in advocacy activities with good, verified evidence and knowledge obtained from direct insight into the problem; collaborative spirit means being well connected with people and organisations dealing in this topic not just in Serbia but also globally and this provides essential insights and

experiences of other countries addressing the issue of elder abuse through public policy. However, this should include working with stakeholders in the field of elder abuse, but also with human rights advocates in general and more specifically, those working on protection of rights of specific population groups (women, persons with disabilities etc.). Our advantage working through the Red Cross is being able to amplify the message both to local communities, using the network of the Red Cross of Serbia, as well as at global level through the International Red Cross Red Crescent Movement.

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Chapter 17
The Emerging Role of Independent Advocacy in Responding to Issues Affecting Older People in Ireland

Mervyn Taylor

> A son can bear with equanimity the loss of his father, but the loss of his inheritance may drive him to despair (Machiavelli)

17.1 Introduction

While the term 'independent advocacy' is relatively new in an Irish context and advocacy as a practice is still contested territory and a source of some suspicion among professionals and service providers it does, nevertheless, have deep historical roots. The act of individuals or groups speaking up for others in order to ensure that their interests are represented is, of itself, timeless. During the twentieth century, out of a diverse range of movements concerned with human, civil, social and political rights for the individual citizen, there emerged concepts, practices and services which can be broadly described as advocacy.

The right to have your voice heard and to participate in making decisions which affect you is a fundamental principle in a democratic society. It is a principle simply stated as: 'Nothing about you/without you.' Many people face challenges to their independence due to physical, intellectual, physical or sensory disability, mental health difficulties, lack of family and community supports or an inability to access public services that meet their needs. Some people communicate differently and with difficulty and some people slowly lose their ability to make and communicate decisions when a condition, such as dementia, develops over time. Some are abused and exploited because of their vulnerability. Others feel disregarded or let down by healthcare services while some are harmed through adverse events or medical negligence.

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In circumstances where people may be vulnerable, or have to depend on others, there is a need to ensure that their rights, freedoms and dignity are promoted and protected. Through support and advocacy the will and preference of a person can be heard and acted on independently of family, service provider or systems interests.

17.2 The Development of the Concept of Advocacy in Ireland

In 1996, the report of the Commission on the Status of People with Disabilities (Flood 1996) recommended that advocacy should be provided for residents in institutional settings and that a legislative framework should be developed to underpin this in order to ensure access to essential social services and vindicate the rights of people with disabilities. Other forms of advocacy, such as self-advocacy and citizen advocacy were also suggested in what was the first reference to the need to develop advocacy in a modern Irish context. While mental health legislation (Mental Health Act 2001) made provision for legal advocacy in reviews of involuntary detention, it is possible to speculate that no broader understanding of advocacy was even considered in the context of people with mental health difficulties. Further legislative developments with regard to people with disabilities (Disability Act 2005) led through a series of independent advocacy initiatives to the eventual development in 2014 of a National Advocacy Service for People with Disabilities (NAS) funded through the Citizens Information Board under the aegis of the Department of Employment Affairs and Social Protection. With the establishment of the Health Information and Quality Authority in 2009 and the regulation of nursing homes for older people, references were made to the need to make provision for people to have access to independent advocates (Health Information and Quality Authority (HIQA) 2016). As there was no legislative underpinning of independent advocacy, many nursing homes simply ignored the issue; some genuinely sought to provide access and found problems with availability and some few denied access to such advocates.

The Assisted Decision Making (Capacity) Act 2015 and the related establishment of a Decision Support Service in Ireland provides the context for the Irish government to comply in full with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (in particular with the provisions of Article 12 of the Convention and with the interpretation of Article 12 by the UN Committee on UNCRPD. This is being progressed further at present through the processing of Safeguarding Adults legislation which is linked to the work of Safeguarding Ireland. The Law Reform Commission is now engaged in work to inform the development of Adult Safeguarding Legislation and it is understood that this will include provision for a formal role for independent advocates. Codes of Practice being developed by the Decision Support Service include one for the guidance of persons acting as advocates which could provide statutory recognition for the term independent advocacy.

While progress in recognizing the role of independent advocacy and providing a legislative and regulatory framework in which it can operate continues at a slow pace, the direction of the journey, if not the exact point of arrival, is becoming clearer.

The Disability (Miscellaneous Provisions) Bill (Houses of the Oireachtas 2016) and a proposed Deprivation of Liberty Bill will address outstanding issues related to the UNCRPD including the protection of liberties of people in places of care where issues of custody are involved and independent advocacy may be required (Browne 2018).

17.2.1 What Is Independent Advocacy?

Independent advocacy can be viewed at two levels – the individual and the systemic.

At individual level, the focus is on the 'voice' of the person, of understanding their wishes, gathering information to enable them make informed choice regarding such options as may exist or be created and supporting them to determine their own best interests and exercise their will and preference. It is about enabling a person to engage in autonomous decision-making and self-determination, protecting people's human and legal rights, safeguarding and protecting vulnerable adults from abuse in all its forms. All of this can be summed up in the motto chosen by Sage Advocacy 'Nothing About You/Without You'. In the case of an individual who has significantly reduced decision-making capacity or who has lost all decision-making capacity, the challenge of ensuring that decisions are made on that person's behalf, which are in keeping with their will and preference, is potentially more challenging. For example, faced with a vocal group of adult children, determined to ensure what they believe to be in the best interests of their parent is carried out, it can be extremely difficult for any independent advocate to ask hard questions regarding whose best interests are being addressed.

At systemic level, the issues of concern to a range of individuals which are similar in nature, or which share the same root cause, can be addressed by independent advocacy. This can involve a range of approaches including: lobbying for legislative and policy change to address gaps in provision where these have been identified; building collaborative platforms for identifying and managing change; identifying advocacy champions at various levels. Independent advocacy can therefore be described as advocacy which is independent of family, (service) provider or systems interests. Having developed sufficient knowledge of the issues of concern to individuals, the challenge for providers of independent advocacy is to ensure an effective balance between addressing the needs of individuals, as they express them, and addressing the underlying issues which consistently give rise to those needs (see also Chap. 16 by Todorovic and Vracevic).

17.3 Some Issues Affecting Older People in Ireland

The range of issues/challenges facing older people in Ireland are well documented through many years of policy development. Initiatives ranging from The Irish Longitudinal Study on Ageing (TILDA)[1] to the Forum on Long Term Support and Care of Older People (Sage Advocacy 2016) have added rich data, insights and assessments of public opinion. Societal preparation for ageing has been greatly assisted by programs such as Age Friendly program,[2] the Dementia Strategy (Department of Health 2014) and the National Positive Ageing Strategy (Department of Health 2013). A noticeable feature of all discourse on ageing in Ireland is the extent of unanimity on policy and concern with implementation. This is well expressed in a key question posed in the Report of the Forum on Long Term Support and Care for Older People; "Why, despite decades of policy reports and recommendations to government, is there still a systemic bias towards care in congregated settings and no formal legislative basis for support and care in the community?" (Sage Advocacy 2016: 6). This bias is reflected in the fact that a Nursing Home Support Scheme (Department of Health 2017) was established in 2009 and is heavily regulated whereas a statutory home care scheme is still some years away as is regulation of home care service provision. The fact that policy statements emphasize a 'continuum of care' and actual implementation focuses on two separate statutory schemes amply illustrates the gap between rhetoric and reality.

Income supports for older people are, from the perspective of outside observers, adequate and the system of 'Free Travel' for older people is still regarded as an important achievement. The role played by social transfers (such as the state pension for older people) in mitigating some of the harsher effects of public spending austerity following the economic crash in 2008 has been highlighted even if has not always been appreciated (McGill 2014).

While the emphasis on nursing home care as the primary response to long term support and care is widely criticized and support for better provision of support and care in the home is growing, there has been little public discussion about the denial of the basic legal and human rights of older people which can arise when care and custody become blurred and a placement of an older person in a congregated care setting against their will and without protections for their rights becomes, in effect, deprivation of liberty. The Citizens Assembly in 2017 held two sessions on the Opportunities and Challenges of an Ageing Society (Citizens Assembly 2017). It heard powerful testimony from a woman who had 'escaped' from a nursing home and returned to live at home despite the efforts of her family and the nursing home (which included threats to call An Garda Síochána (Irish Police)) to convince her to stay. The long delay in the implementation of the Assisted Decision Making

[1] See https://tilda.tcd.ie/publications/

[2] The Age Friendly Cities and Counties Program is run by city- and county-based Alliances, involving senior decision-makers from public, commercial and not-for-profit organizations.

(Capacity) Act of 2015 has meant that the Lunacy Regulations (Ireland) Act of 1871, and the system of wards of court which formed the backdrop to Charles Dickens great novel 'Bleak House', has meant that there are now at least 2600 people[3] subject to care and custody without adequate checks and balances to protect their rights.

A related issue where care and custody become blurred can be noted with regard to delayed discharges from acute hospitals or, as they are more appropriately termed within the NHS, 'delayed transfers of care'. Gaining access to necessary healthcare in an acute hospital can be difficult with significant waiting times and sometimes degrading treatment involved in emergency departments through which an enormous level of hospital admissions are made. Despite these pressures on hospital beds, the process of discharge from hospital, in the absence of appropriate homecare or because of a risk-averse approach by hospital staff, can lead to older people being effectively detained against their will. In extreme circumstances, periods of many months can be involved. A further issue relates to older people at end of life whose expressed wish to die in their own home remain unconsidered as the institutional pull of acute hospitals wins out over the policy priority of home care. The dominance of hospitals and nursing homes in the landscape of Irish health and social care provision both reflects and reinforces the medical model of care and marginalizes opportunities for innovation with regard to new models of support and care focused around housing with supports.

If the instincts of too many in the healthcare system reflect a 'best interests' approach and a willingness to ignore the possibility that some care provision has aspects of custody, it is only fair to point to the lack of systems of review that might address the lack of understanding and skills regarding issues of consent and the authoritarian instincts of some of the medical and nursing professions. Even in the area of safeguarding of vulnerable adults, the Irish Health Service Executive (HSE) states that its Safeguarding and Protection Teams cannot intervene on a matter of concern regarding an older person in a private nursing home in the same way that they can intervene in a HSE owned facility.[4] It is interesting to note that the Report of the Commission on Policing (Commission on the Future of Policing in Ireland 2018), while necessarily addressing issues of state security, is heavily focused on the protection of vulnerable people and the need to respect human rights. The nearest equivalent report in a health and social care context is the all-party Sláintecare Report (Committee on the Future of Healthcare 2017) which does not consider the issue.

[3] https://www.irishtimes.com/news/crime-and-law/more-than-2-600-judged-incapable-protected-as-wards-of-court-1.3356429

[4] This was pointed out in a Letter of 13th August 2018 from the Chair of Safeguarding Ireland (National Safeguarding Committee) to the Minister for Health which suggested a way out of this.

17.4 Developing a Response

Any strategy which seeks to address the issue of rights within the systems of health and social care provision must take account of the emerging potential arising from a diverse range of issues and initiatives and be sufficiently innovative and flexible to enable linkages where these may not be immediately obvious. Health, social care and legal professions are products of and are influenced by the society and economy within which they operate. Key to the development of any strategy has to be the development of professional awareness as part of a wider process of developing public awareness. An example of this is the belief, widespread among professionals and the public that people who are 'next of kin' have a level of decision-making authority over a close relative in certain circumstances. Research undertaken for Sage Advocacy by Red C (2018) found that over half (52%) of those questioned believed, that anyone named as 'next of kin' can make healthcare or other major decisions on another person's behalf. In fact, being named as 'next of kin' means no more than that the named person should be contacted in the event of an emergency. The widespread belief in the powers of 'next of kin' has contributed to older people being placed in nursing homes against their will, contracts being signed on their behalf without their involvement, control and dispersal of funds and assets, interference with healthcare procedures and considerable wastage of valuable time by professionals who have to engage with and often mediate between competing factions of an extended family. An initiative to promote awareness of existing consent policies in the health and social care services reinforced with a change of wording on all paper and digital records systems to delete references to 'next of kin' and include a question regarding 'who you would like information shared with' would do much to change popular and professional understanding and reinforce the rights of older people in a practical way.

At a higher level, the 2018 Hogan judgment[5] which clearly pointed to the need for legislation to address issues of custody in care situations, has implications for the operation of the system of wards of court which does not provide the same rights for older people being considered for wardship as a mentally ill person detained under the Mental Health Act 2001. The passing of legislation to provide rights for people being considered for placement in care settings and the full implementation of the Assisted Decision-Making (Capacity) Act 2015 which will lead to the phasing out of the system of wards of court point to the potential for progress. However, the extent of progress depends on the convergence of a number of developments with the associated hope that synergy will develop. It also depends on the extent to which independent advocacy can contribute to the integration of issues and initiatives by making plain the extent to which they are all related and by being able to

[5] In a Court of Appeal Judgment on whether a hospital had a right to detain a person against their will, Justice Gerard Hogan stated that the court was not satisfied that the hospital had the power to detain the person which he said amounted to paternalistic entitlement to act in the best interests of the patients whose capacity is impaired and, in effect, to restrain their personal liberty and freedom of movement.

provide practical supports to individuals and groups of people who are especially vulnerable so as to build awareness of rights and responsibilities.

Recognition of the importance of rights and of the need to reinforce them through growing awareness needs to be balanced by an understanding that other social and familial dynamics can have an impact. Popular perceptions of decision-making rights can be reinforced by beliefs related to inheritance. The well-intentioned desire of a parent or grandparent to pass on something to children or grandchildren can create an ill-intentioned belief in the right of the younger to an inheritance from the older. It can also mean that those older people who have committed their intentions to paper, in the form of a will, can then find it difficult to change their will if circumstances change or their understanding of their offspring's motivations changes. The desire of many older people to be self-reliant can be self-defeating when physical health declines, frailty increases and they start to feel that they may be a burden on their own family. In such circumstances older people can be extremely vulnerable to abuse as adult children start confusing the best interests of their parent or grandparent with their own interests. Creating awareness of these issues among older people may require a judicious mix of counter-intuitive media efforts as well as changes in inheritance law and taxes. It may also require a system of incentives to people to plan ahead; in effect to advocate for themselves when they may at some future stage be unable to by making clear what their wishes are with regard to healthcare, places of care and decision-making in the event that they lose the capacity for decision making. Such a system of incentives must include not just incentives to the public to engage with resources such as 'Think Ahead' (Irish Hospice Foundation n.d), Advance Healthcare Directives and Enduring Power of Attorney, but also incentives to healthcare professionals to promote these measures with patients at appropriate times. Crucial to the success of such an approach is an incentive to health and social care systems to enable speedy access to information regarding the forward decision-making plans of individuals and thereby minimizing the extent of time and resources expended in engaging with family members with differing interpretations of what a person might or might not want. While the evidence regarding usage and effectiveness of instruments for forward planning such as Advance Healthcare Directives and Enduring Power of Attorney is still limited, the desirability of people being provided with a means to have their voice heard when they no longer have a voice remains morally compelling. Backed by state incentives and a determination to undertake cost-benefit analysis, the overall effect could well be a reinforcing of the rights of older people.

17.5 The Role of Independent Advocacy

The development of responses to these issues, from an advocacy perspective, must take into consideration the nature of independent advocacy, the context in which it currently operates and the emerging landscape in which it will have to operate. Independent advocacy, to borrow a phrase from Victor Hugo, is 'an idea whose time

has come'. The slowly changing legislative context, which will likely provide legislative recognition for the practice of independent advocacy, reinforces the growing support for person-centredness (see Chap. 3 by Phelan and Rickard Clarke). Insisting that a vulnerable person, or group of vulnerable persons, has a right to have their voice heard and their will and preference (wishes) taken into account challenges service providers to put meaning into the term person-centredness. But, if in an ageing society vulnerability remains inextricably linked with frailty and increasing frailty over extended periods is the result of increasing longevity (Kingston et al. 2018), then the inevitable need for increased health and social care provision will have to be accompanied by greater provision of advocacy services. The difficulty here is that resources will have to be prioritized. Simple choices will have to be made between, on the one hand, providing additional professionals who can deal with specific clinical and social issues in the context of constrained resources and, on the other, providing people to advocate for individuals so that they can access existing services as well as lobbying for the provision of additional resources. Such an approach will, undoubtedly, involve 'speaking truth to power', but it will also mean 'speaking truths to the powerless'; to tell them hard facts about limited and possibly non-existent options. This poses the question: 'how can advocacy be more strategic in its practice and interventions?'

One of the problems associated with the practice of advocacy is that it is often called for when situations have already become complicated as a result of many professionals with differing perspectives and limited control over necessary resources being unable to progress issues. To add to the complications, the families of the vulnerable person may be unable to act collaboratively; the difficulties may be even further compounded if one or more of the family are exploiting the vulnerability of the older person in some way. Viewed from this perspective, if paramedics are first responders then advocates are last responders.

Meaningful responses to these challenges will require a greater focus on strategy and tactics than resources. There is a need to recognize that the principles and process of advocacy do not just belong to advocacy services. In practice, as many service providers are willing to advocate for vulnerable people as are the number of those likely to be challenged by and block access to independent advocacy. A layered advocacy response is required in which the advocacy roles of professionals are recognized as a resource but its limitations are also recognized and addressed through judicious use of independent advocacy, i.e., advocacy which is independent of family, service provider or systems interests. The development of a systems culture in which the differing advocacy roles of professionals, family members and independent advocates can operate is of crucial importance. While many advocacy providers regard self-advocacy as the 'gold standard' of advocacy, without any sense of irony, it is the experience of Sage Advocacy that representative advocacy is frequently required by vulnerable adults, older people and healthcare patients. There is, however, an approach which seeks to develop the role of 'advocacy champion' within care providing organizations; a role which acknowledges that service providers can act within agreed parameters within an organization or service while

relying on the support and, where necessary, the intervention of an independent advocate. Such a role emphasizes the need for the advocate to collaborate, where possible, as well as to challenge, where necessary. Creating an awareness of an advocacy spectrum of self-advocacy, advocacy champion and independent advocacy has the potential to give practical expression to the concept of person-centredness.

The development of advocacy responses to complex issues involving multiple levels of support and care provision across a range of providers is enormously challenging, particularly in a context in which vulnerability often tips the scales of judgment towards safeguarding rather than autonomy, is enormously challenging. In circumstances of multiple morbidities, complex systems of provision and conflicts of interests, advocacy can be most effective if it is combined with the skills of mediation and systems integration. This suggests that advocacy services might need to become 'service brokers' as part of the process of gathering information, explaining options and supporting people to make decisions.

If advocacy can reinforce person centredness, respect existing professional roles while gaining respect for its own important contribution, and push its own boundaries to deliver better outcomes for vulnerable people and innovation in service delivery, it is going to need to develop and progress an agenda which can demonstrate both its unique contribution and the extent to which it can complement the work of health, social care, legal and financial professionals. If the term independent advocate is to be a 'protected term' (Quinn 2018) and if legislation to provide a role for independent advocacy in the context of deprivation of liberty and safeguarding vulnerable adults is increasingly seen as more rather than less likely, it is time that some form of support and oversight structure be put in place to address core issues such as standards, training, funding, and coordination. The development of a National Council for Advocacy must now become part of the wider strategy of all those concerned with safeguarding vulnerable adults and older people.

The collaborative as well as the challenging nature of advocacy and its practical role in acting as a systems integrator in support of individuals has the potential to provide momentum to the development of structures and systems for safeguarding vulnerable adults. Responsibility for dealing with abuse of older people has been the responsibility of the health and social care services for many years. In particular, responsibility has been exercised through social workers organized since 2015 in Safeguarding and Protection Teams.[6] While there is anecdotal evidence that the resourcing of such teams is only about one third of what it should be, it is clear that the provision of resources alone is not sufficient. The report of the Commission on the Future of Policing in Ireland states that:

> Police increasingly find themselves dealing with the most vulnerable members of society – those who are unable to protect themselves from coming to harm or suffering exploitation. (Commission on the Future of Policing in Ireland 2018: 13).

[6] These teams were established within the HSE Social Care Division following the publication of the Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures (2014).

The report also argues that:

> …the prevention of harm should be explicitly identified as a core objective of policing… [and that]…police need to be equipped with the necessary special response techniques required in incidents involving vulnerable individuals who may not react well to typical police interventions. (Commission on the Future of Policing in Ireland 2018: 13).

The placing of vulnerable people, including vulnerable older people, at the heart of policing strategy is a significant development and the report also refers to the potential for integrated teams of Gardaí and social services working in shared accommodation, something recommended by the Mental Health Commission some 9 years ago (Mental Health Commission/An Garda Síochána 2009).

The experience of Sage Advocacy on the ground suggests that inter-agency collaboration to safeguard vulnerable adults is still, in many respects, a half-conscious thought. While the difficulties of inter-agency working have been highlighted and the need for processes of collaboration underlined (McKeown 2012),[7] it is clear that a core of agencies, already represented on Safeguarding Ireland (the National Safeguarding Committee) such as the HSE, HIQA, An Garda Síochána and the Department of Employment and Social Protection could, by working together and by being informed by the work of services such as Sage Advocacy, develop useful guidelines and effective practices which could mean that if, for example, independent advocacy were to be afforded legal recognition of its practice but not legally enforceable powers (such as access to documents and premises), it would have ready access to all those key players who in differing ways are charged with safeguarding and protecting vulnerable people and their interests.

17.6 Conclusion

In her Foreword to the Quality Standards for Support and Advocacy Work with Older People, the then Justice of the Supreme Court, Mary Laffoy stated:

> Too often we see the issues facing older people as related solely to health and social care. In doing so we can sometimes forget the fundamental importance of values, standards and the law in determining the wellbeing of citizens. (Sage Advocacy 2015: 3).

The experience of developing support and advocacy services for older people in Ireland and further developing them to include vulnerable adults and healthcare patients suggests that the implementation of the laws enacted or emergent will be accompanied by a long and challenging battle between two opposing values: best interests and will and preference.

[7] McKeown points out that an effective and inclusive inter-agency process is necessary but not enough for improving child outcomes; the sufficient condition for improved child outcomes is effective intra-agency processes to deliver high-quality services and a policy environment that supports and requires it.

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