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Supporting inclusion of people with cognitive disabilities

Literature Review of Best Practice Supports in Disability Services for the Prevention of Abuse of People with Disability

Report for the Disability Services Commissioner

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Executive summary

Background

Epidemiological research suggests that compared to the general population people with disabilities experience significantly higher rates of abuse and that people with intellectual disabilities and those who reside in residential services are at particularly high risk. The socio-ecological framework conceptualised violence and abuse as an outcome of complex interrelationships between individual characteristics, their social and physical environment and the cultural context. In recent years policy makers, researchers and advocates have acknowledged the extent of violence against people with disabilities with a wide array of prevention strategies described in the scholarly and grey literature.

Aim

This report aims to map this broad literature on the abuse of people with intellectual disabilities and identify: 1) personal, environmental and relational aspects, as well as factors in service environments and organisational cultures associated with the vulnerability of people with intellectual disabilities to violence and abuse; 2) preventative abuse strategies for people with intellectual disabilities, and, 3) review the evidence about the quality and effectiveness of these strategies.

Method

A literature review was conducted to identify epidemiological data on abuse and its impact, as well as to identify risk and protective factors for abuse among people with intellectual disabilities in residential care. A systematic scoping review was conducted to identify relevant studies published in the last 10 years in the peer review and grey literature evaluating abuse prevention interventions.

Findings

Risk factors for violence and abuse. An emerging body of literature attempts to understand factors associated with the higher prevalence of abuse against people with intellectual disabilities, in general and in disability services in particular. Most of this literature has its foundations in the socio-ecological framework and defines the person's vulnerability to abuse as an outcome of an interactive process between the social context in which the person lives and a set of underlying personal factors, that when present place the person at risk of abuse.

Individuals with disabilities - personal risk factors. Some scholars have identified the severity of the cognitive impairment and associated characteristics (such as challenging behaviour and communication difficulties) as risk factors to abuse. Additionally, many of the risk factors identified in the general population are particularly prevalent among people with intellectual disabilities. These include poverty, low self-esteem, unemployment, poor-quality health care, exposure to history of

violence and abuse, restricted access to essential services, dependency on others, smaller social networks, inadequate housing, and social stereotypes of vulnerability. Other risk factors for people with intellectual disability are associated with living in residential care services, social isolation, contact with multiple potential perpetrators and socialisation to compliance. Several scholars have also suggested higher vulnerability of women to abuse compared to men (Brown & Turk, 1994; Smith, 2008; WWDA, 2017). However, other epidemiological surveys and reviews have failed to document this difference (Hutchison & Stenfert Kroese, 2015; Peckham, 2007), hence the association between gender and abuse remains underdeveloped. A critical examination of the literature reveals several challenges that hamper the ability to draw a conclusions about the association between gender and vulnerability: first, most of the research conducted in this area has focused on sexual abuse of women with intellectual disability and is mostly limited to descriptive information retrieved from case records or small qualitative studies of the experiences of woman who has been sexually abused (without using control groups) (Teaster et al, 2007). Secondly, in many cases the data does not distinguish between different types and severity of disability or residential settings (Hutchison & Stenfert Kroese, 2015). Thirdly, it has been suggested that the existing data may be biased as cases of abuse of men are often not recognised and underreported. Finally, as mentioned above, it seems that statistical prevalence data is limited and does not allow a rigorous comparison between men and women with intellectual disabilities.

Perpetrators of abuse - risk factors. The literature suggests that in most cases of abuse the perpetrators are known to the victim, with multiple studies identifying personal characteristics of perpetrators such as male gender and age as risk factors. In addition, having a history of abuse as a victim or a perpetrator was also associated with further incidence of abuse. Another body of research established higher prevalence of particular personality traits (external locus of control) and personality disorders (psychopathy, narcissism and sociopathy) among perpetrators of abuse.

Organisational environments - risks or protective factors. Research on the quality of supported accommodation services has identified a bewildering array of interacting variables associated with resident outcomes (abuse or opposite quality of life and safety). These indicators may be captured under the conceptual framework of organisational culture. Research has identified associated cultural indicators, including the skills and attitudes of managers, skills and training of staff, organisational procedures, values and care philosophies. These indicators found in the literature were evaluated using rigorous observational methods in Australian group homes. This research has culminated in five evidence-based dimensions of organisational culture: 1) Alignment of power holder values; 2) Regard for residents; 3) Perceived purpose; 4) Working practice; 5) Orientation to change and ideas.

Preventative abuse strategies for people with intellectual disabilities. The systematic search for evaluations of the effectiveness of interventions to prevent abuse against persons with intellectual disabilities identified six studies that met the inclusion criteria. These studies can be categorised into three groups based on methods of training and target population: 1) Behavioural-skills training; 2) Training using a cognitively oriented decision-making; and 3) Psycho-education training for care staff or individuals with intellectual disabilities.

Discussion and conclusion

The review reveals that the notion of prevention strategies has been discussed in the peer-reviewed and grey literature, and many intervention strategies have been designed and implemented over the years. Despite this, only a very small fraction of them have been rigorously evaluated, and these all relate to primary prevention strategies predominantly targeted at individuals with mild to moderate intellectual disability.

Given this paucity of evidence, it seems that in order to establish “evidence-based” effective prevention strategies and to reduce the prevalence of abuse and violence in the lives of people with intellectual disabilities, research and interventions need to evolve from the response-to-risk approach to a broader framework encompassing the individual’s safety as part of their quality of life. Relying on the evidence-based indicators of organisational culture identified in the literature may prove fruitful in promoting good quality of care that is associated with better safety and quality of life outcomes for individuals with intellectual disabilities.

Literature Review of Best Practice Supports in Disability Services for the Prevention of Abuse of People with Disability

Introduction

Violence and abuse against individuals with disabilities is a serious public issue. The two groups of people with disabilities most at risk, are people with intellectual disability and those who live in residential settings (Didi et al., 2016; Dowse et al., 2013; Lan-ping et al., 2009; Levy & Packman, 2004; Ortoleva & Lewis, 2012; Ottmann et al., 2016; Women with Disability Australia [WWDA], 2012; 2011). Abuse is a complex phenomenon that can only be understood as an interactive process between individual characteristics and sociocultural contexts (Fisher et al., 2016; White et al., 2003)

By ratifying the United Nations Convention on the Rights of Persons with Disabilities (2006), the Australian government declared its obligation to ensure the human rights of people with disabilities and to combat abuse. The Convention mandates state parties to “take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects”. Similarly, at the State government level, the Victorian Disability Act 2006 sets out the rights of people with disabilities to respect and dignity, recognising their human rights to “live free from abuse, neglect and exploitation”. Such rights are also reflected in the Victorian Charter of Human Rights and Responsibilities Act 2006 (Vic). These pieces of legislation require governments to take appropriate measures to "prevent all forms of exploitation, violence and abuse" and ensure "assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse”. In a sector wide partnership National Disability Services developed the Zero Tolerance initiative which took a holistic approach to abuse prevention (Robinson, 2015). This initiative offers disability services an overarching framework for understanding the causes of violence and abuse that informs interventions to improve practice aimed at safeguarding the rights of the people they support (National Disability Services [NDS], 2016)

Increasingly, over the last decade, policy instruments and research acknowledge the extent of violence against people with disabilities, and a wide array of prevention strategies are described in the scholarly and grey literature. Despite, growing attention to this issue, there is however, little evidence about effectiveness of interventions to inform the prioritisation of effort, and frameworks are largely conceptual rather than evidence based. More rigorous evaluation is required to establish

the effectiveness of abuse prevention strategies to advance evidence-based practice in this field (Northway et al., 2007; Perry, 2004; Quarmby, 2011; Robinson & Chenoweth, 2011; 2012).

In this report, commissioned by the Disability Services Commissioner, we provide a brief review of the broader literature on abuse of people with intellectual disabilities, and analyse the scholarly research literature on the effectiveness of abuse prevention strategies. Our focus is particularly on those in receipt of disability services who are also often those with higher support needs and more severe levels of intellectual disability.

We note that much of the literature does not differentiate between people with disabilities in general and people with intellectual disability, and refers to violence and abuse. We use the term abuse throughout this report to refer to both violence and abuse unless a source has differentiated between these terms.

Using a socio-ecological model of abuse as the conceptual framework we seek to identify: 1). Personal, environmental and relational aspects as well as factors in service environments and organisational cultures associated with the vulnerability of people with intellectual disabilities to abuse, and; 2). Preventative abuse strategies for people with intellectual disabilities, and evidence about the quality and effectiveness of these strategies. This critical analysis of the literature identifies core elements and strategies used in prevention of abuse of people with intellectual disabilities, highlighting the strengths and gaps in these strategies.

Definitions of abuse

Abuse is broadly defined as a violation of an individual's human or civil rights, through the non-accidental act or actions of another person or persons (Cooper et al., 2008). This definition includes physical, sexual, verbal, psychological or emotional abuse, constraints and restrictive practices, financial, legal, civil and systemic abuse, and may consist of a single act or repeated acts. The scope of this review includes sexual, physical and emotional abuse defined by the National Disability Abuse & Neglect Hotline as (Department of Social Services, 2016):

- Physical abuse - inflicting physical injury, pain or any unpleasant sensation.
- Sexual abuse - sexual contact with a child aged 16 or under. Sexual activity with an adult who is unable to understand or who has been threatened, coerced or forced.
- Psychological or emotional abuse - verbal assaults, threats, harassment, humiliation or intimidation. Failure to interact or acknowledge a person's presence.

In the context of abuse in community care environments it is important to note that abuse may be a continuum of circumstances and its definition determined by the impact on the client. In disability services, difficulties in establishing “exactly where to draw the line of inappropriate/non-optimal and the unacceptable” (Cashmore et al., 1994) are compounded by the fact that many people with intellectual disabilities are unable to recognise and report abuse. Therefore, defining whether abuse has occurred must take into account, not only the nature or intent of the alleged perpetrator's actions (and whether these reach a criminal threshold), but also the experience of the individual with the disability and the impact on their physical and psychological well-being (Cashmore et al., 1994; Sobsey, 1994). The Victorian Law Reform Commission's recommendation that abuse of people with impaired decision making should be regarded as a new "public wrong" supports this view, suggesting civil penalties and noting that whilst abusive behaviour may constitute a criminal offence of assault, “It is important, however, that abuse of vulnerable people be characterised as a public wrong in some circumstances, even when criminal proceedings are unavailable or unlikely to succeed” (Parliament of Victoria, 2015).

A conceptual model of understanding abuse

No single factor can explain why abuse of people with intellectual disability occurs and persists. Its causes are commonly conceptualised as the complex interrelationship between individual characteristics, their social and physical environment and the cultural context (Fisher et al., 2016; Terry et al., 2014; White et al., 2003). The socio-ecological framework is the conceptual model proposed by the World Health Organisation for exploring abuse in the lives of vulnerable populations, and the model most frequently used in the literature (Fitzsimons, 2017). As Figure 1 illustrates, in this model, abuse is conceptualised as an outcome of the complex interaction of factors at four levels of analysis: individual, relational, community and broader societal context.

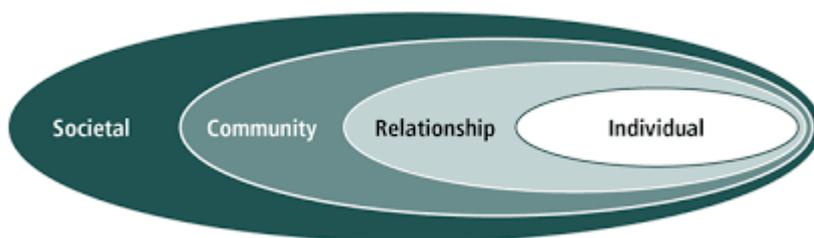


Figure 1: Socio-ecological model for understanding abuse, violence, risk and protective factors

Source: Krug, et al., 2015.

The *individual level* includes personal health and socio-demographic characteristics of the victim and perpetrator, and is associated with higher risk of exposure to abuse.

The *relational level* includes characteristics and types of interaction between the individual and their immediate social network in personal and professional settings.

The *community level* is the social context in which social relationships occur, such as disability services, neighbourhoods and workplaces.

The *broader societal context* comprises the factors that influence whether violence is encouraged or inhibited in the society more widely, and the economic and social policies that maintain inequalities between people, and social and cultural norms such as those around disability.

The socio-ecological framework regards the interaction between factors at different levels with equal importance to the influence of factors within a single level (Fisher et al., 2016; White et al., 2003).

For example, Sobsey's (1994) socio-ecological theory of abuse of people with disability focussed on interpersonal relationships between carers and people being supported in the context of power differences. He demonstrates how, in this context, reinforcements such as social isolation and dehumanisation of individuals with intellectual disability exist in the community and societal levels that allow abusive relationships to continue.

The socio-ecological framework is also useful for identifying and clustering intervention strategies according to the level in which they act. For example, psycho-educational and skill development interventions act at the individual level to strengthen the person's ability to recognise abusive situations and react in a manner which may reduce the abuse. Strategies targeting the community level entail interventions aimed on monitoring and developing a "protective organisational culture" in disability services.

The scholarly literature suggests that compared to the general population people with disability experience significantly higher rates of abuse and it is asserted that people with intellectual disabilities are at particularly high risk (Didi et al., 2016; Dowse et al., 2013; Lan-ping et al., 2009; Levy & Packman, 2004; Victorian Ombudsman, 2015; WWDA, 2012; 2011). However, there is no strong statistical evidence of these claims. The omission of people with disabilities from national data collection strategies means there is no reliable national data on the prevalence, extent, nature, and impact of abuse against individuals with intellectual disabilities in the range of settings in which they receive support (WWDA, 2012). For example, the Australian Personal Safety Survey, the core database that captures prevalence and type of violence at a population level, excludes individuals with disabilities with communication difficulties and those who reside in settings other than private

dwelling (WWDA, 2012; 2011). A search of the international literature reveals similar knowledge and methodological gaps in other Western countries.

Epidemiological research has found wide variation in reported incidence of abuse, often accounted for by the absence of consistent definitions of both abuse and disability. For example, one review of the prevalence of abuse of people with disabilities, found rates ranging from 26% to 90% over the lifetime of women with disabilities and 28.7% to 86.7% for men (Hughes et al., 2012). A different approach to exploring the incidence of abuse among individuals with intellectual disability was taken by Beadle-Brown et al., (2010) who analysed UK adult protection cases, which include a broad range of vulnerable groups. Their analysis of cases between 1998-2005 found that 32% of the reported abuse cases involved individuals with intellectual disability.

The most common types of abuse reported in the Beadle-Brown et al. (2010) study were physical (29%) and sexual (17%). Furthermore, 33% of the reported cases identified multiple types of abuse, mostly physical combined with psychological abuse, and 13% of the cases involved multiple perpetrators. Similarly, an analysis of 494 confirmed cases of neglect and abuse in public residential facilities for people with intellectual disabilities across six US states found that 80% involved physical abuse (McCartney & Campbell, 1998)

The literature suggests that most cases of abuse occur in institutional or service settings, and that in most cases perpetrators are known to the victim. For example, a UK study found that most (63%) adult protection cases involving people with intellectual disabilities occurred in residential care service and the most frequently reported perpetrators were direct care staff (Beadle-Brown et al., 2010). Similarly, a UK 15-year longitudinal study of 118 confirmed cases of sexual abuse found that in 99% of cases involving sexual abuse of people with intellectual disability the perpetrator was known to the victim (McCormack et al., 2005). In this study 54% of the perpetrators were peers with intellectual disabilities and 43% were people involved in the care of the person. Earlier studies by Brown et al. (1995) also identified that perpetrators were predominantly either family, paid staff or peers with intellectual disabilities. Similarly, in their analysis of 161 cases of sexual abuse, Sobsey and Doe (1991) found that while abusers can be strangers (8%), casual acquaintances (15%), or other individuals with disabilities (7%), most commonly they are a family member or a paid service provider involved in the care of the person with a disability.

Estimates of abuse vary widely, depending on the definitions of abuse and disability used, and data collection methods. This limits comparison of data between vulnerable groups and the general population. Indeed, Murphy (2007) and Brown (1995) point out that the available data on the

incidence and prevalence of abuse perpetrated towards people with intellectual disability is likely to be only the 'tip of the iceberg' given the poor recognition and under-reporting of abuse. The fact that victims of abuse are more likely to know, live and rely on their perpetrators for care adds an additional layer of complexity to the understanding of the phenomena (Murphy, 2007).

Impact

Research shows that abuse has far-reaching and life-long consequences for victim's physical health, well-being and socio-psychological functioning (Anda et al., 2006; Brown et al., 2009; Knudsen et al., 2006; Mercy & Saul, 2009; Shonkoff et al., 2009; Shonkoff & Garner, 2012). However, while consequences have been studied in the general population, little systematic research has explored the impact of abuse for people with intellectual disabilities in care service systems (Murphy et al., 2007; Rowsell et al., 2013; Wigham et al., 2011).

The little research there is indicates that people with intellectual disabilities experience similar detrimental effects of abuse to those found in the general population. A study exploring the psychological impact of abuse for a small group of individuals with severe intellectual disabilities and very limited communication skills found that family members and care staff perceived victims as displaying increased frequency and severity of emotional, physiological and behavioural symptoms of psychological distress (Rowsell et al., 2013). In a comparison of people with intellectual disability who had experienced abuse with those with no history of abuse, Sequeira et al. (2003) found that people who had been abused displayed higher levels of trauma, anger, depression, self-harm behaviours, withdrawal, anxiety and other stereotypical behaviours. Other studies exploring the impact of sexual abuse on individuals with intellectual disability have found a strong association between a history of sexual assault and challenging behaviours, self-harm and sexualized behaviour (Hulbert-Williams & Hastings, 2008; Rowsell et al., 2013).

Risk factors for violence and abuse

An emerging body of literature attempts to understand factors associated with the higher prevalence of abuse against people with intellectual disabilities, in general and in disability services in particular. Most of this literature has its foundations in the socio-ecological framework and defines the person's vulnerability to abuse as an outcome of an interactive process between the social context in which the person lives and a set of underlying personal factors, that when present place the person at risk of abuse (Blum et al., 2001).

Individuals with disabilities - personal risk factors

Some scholars propose that the very characteristics associated with intellectual disability are a key risk factor for abuse on the basis that cognitive impairment hampers the individual's ability to recognise and respond appropriately to situations where danger exists (Casteel et al., 2008; McCartney & Campbell, 1998; Rusch et al., 1986). Severity of cognitive impairment magnifies risk as a number of studies have found that the vast majority of people with intellectual disabilities exposed to abuse have severe or profound intellectual disability (Casteel et al., 2008; McCartney & Campbell, 1998; Rusch et al., 1986). Similarly, statistical analysis of abuse cases in US public residential facilities for people with intellectual disabilities, found that having challenging behaviour and communication difficulties increased the probability of being abused (McCartney & Campbell, 1998).

Many of the risk factors of abuse identified in the general population are particularly prevalent among people with intellectual disability. These include poverty, low self-esteem, unemployment, poor-quality health care, exposure to history of violence and abuse, restricted access to essential services, dependency on others, smaller social networks, inadequate housing, and social stereotypes of vulnerability (Fawcett, 2009; Ortoleva & Lewis, 2012; Robinson, 2013). This suggests that the vulnerability of people with intellectual disability to abuse is strongly associated with their socio-demographic characteristics, and societies' structural, social and political responses to their needs (Robinson, 2013).

The dependence of people with intellectual disabilities on others for support as a consequence of cognitive impairment also heightens risk. For example, a number of researchers suggest that, in general, any limitation on one's ability to undertake activities of daily living heightens the risk of abuse (Gilson et al., 2001; Swedlund & Nosek, 2000; Thomas et al., 2008). Further risk factors are associated with living in residential care services (Nosek et al., 2006; Powers et al., 2009), social isolation (Beadle-Brown et al., 2010) and contact with multiple potential perpetrators (Nosek et al., 2001).

Sobsey (1996) argued that the key to understanding the victimisation of people with intellectual disability is their relative lack of power over their own lives. Sobsey contended that people with intellectual disability seldom have opportunities or support to make decisions about the way they live their lives, and have to rely on others, over whom they have little or no control, to meet physical, psychological or economic needs. Other scholars note that people with intellectual disability often lack credibility or "voice" if they do have the opportunity to complain or to express preferences

about the support they receive (Ticoll, 1994; Thomas et al., 2008). Furthermore, their experience of dependence on services may lead to “over compliance” (Mazzucchelli, 2001) or “learned helplessness” (Saxon et al., 2001). These researchers suggest that people with intellectual disabilities in the care system often have a learning history, that reinforces compliance, which may be a further risk factor that means they comply with requests that result in abuse.

Perpetrators of abuse - risk factors

Scholars have explored the characteristics of perpetrators, and suggest that at least some offenders fit specific profiles (Sobsey, 1994). Multiple studies (McCarthy, 1998; Turk & Brown, 1993) identify gender as a risk factor. For example, in their research on referrals to adult protection services in the UK, Cambridge et al. (2011) examined the characteristics of confirmed and alleged perpetrators. They noted that in 93.5% of sexual abuse referrals, the alleged perpetrator was “a man or involved a man” (p. 5). Cambridge et al. (2011) also found that in 46% of the referrals for alleged abuse against individuals with intellectual disability the perpetrator was a staff member or manager involved in the care of the person with the disabilities. Findings regarding the age of perpetrators in services have been somewhat mixed, though more studies suggest that younger staff are more likely to be abusive than older staff. Conversely, McCartney and Campbell (1998) found that staff in residential care who had committed abuse were significantly older than their peers. Strand et al. (2004) found that most perpetrators were either under thirty (41%) or over forty (38%) years of age.

Not surprisingly, having a history as a perpetrator is associated with further incidents of abusing clients. For example, McCartney and Campbell (1998) reported that among staff found to have abused clients, 21.5% had done so on another occasion in the previous year, compared with only 6% of the randomly selected carer group. Other scholars, have identified particular personality traits as being associated with perpetrators of abuse, although not especially among abusers of people with disabilities. Hulme and Middleton (2013) found, for example, that more than 60% of sex offenders “demonstrated an external locus of control” - that is, they did not perceive themselves as having complete control over their emotions and behaviour. This study also found that 87% of sex offenders had experienced “moderate to severe” trauma including high rates of sexual, physical and emotional trauma as a child. Finally, scholars have established higher prevalence of certain personality disorders among perpetrators of abuse, including psychopathy, narcissism and sociopathy (Meloy, 2002a; 2002b; Mouilso & Calhoun, 2016). For example, Meloy (2002a) found a predictive relationship between people convicted of sexual assault and psychopathy. These findings suggest the relevance of psychometrically testing for these traits as part of staff recruitment processes.

Organisational environments - risk or protective factors

Abuse of people with disability who live in residential services occurs in a particular cultural and environmental context (Robinson, 2013). Research over many years, on the quality of supported accommodation services, and reviews of major inquiries into situations of institutional abuse has identified a bewildering array of interacting variables associated with abuse in care service (Bigby et al., 2015; Felce et al., 2002; Hastings et al., 1995; Mansell et al., 1994).

Organisational culture is commonly identified as a key concept for thinking about the way that multiple variables situated across different organisational levels interact and influence service quality and thus service users' quality-of-life (Bigby et al., 2016a; Felce et al., 2002; Hastings et al., 1995; Mansell et al., 1994). A qualitative exploration of services where abuse was known to have occurred identified associated cultural indicators, including the skills and attitudes of managers, skills, attitudes and values of care staff, service design and material quality of accommodation (White et al., 2003; Marsland et al., 2007). These findings reflect earlier research that consistently links management practice, and particularly managerial indifference, to services where abuse and neglect occurs (Cambridge, 1998; Sobsey, 1994; Sundram, 1985). For example, Cambridge (1998) observed that managers in residential services where abuse had occurred were uninvolved and distant from direct care staff and the day-to-day routines. More recently, in respect of care services in general, Rees et al. (2010) suggested that low interaction between frontline staff and management is associated with insufficient professional support and supervision, and may promote an abusive environment.

Related to aspects of culture, research has also identified an association between organisational procedures, values and care philosophies and abuse in care settings. Cambridge (1998) for example showed that services where abuse had occurred were characterised by staff working in isolation away from scrutiny, an absence of constructive teamwork and resistance of input and involvement of outside professionals. Additional indicators of cultures where abuse occurs have been identified as the lack of a strong philosophy of care (Moore, 2001) and lack of a valuing relationship between care staff and individuals with intellectual disabilities (Gray-Stanley & Muramatsu, 2011; Moore, 2001).

Research has consistently found that staff in care service who have been abusive often lack training and experience in these services (Cambridge, 1998). For example, Cambridge (1998) reported that staff who had abused lacked qualifications, professional skills and had low levels of competence and experience in performing essential care tasks. Wang (2005) found that abusive behaviour was significantly correlated with caregiver professional status, educational level/training and burden.

Specifically, those who were younger, less well educated, lacking specific training and who perceived themselves as being more burdened, displayed a tendency toward more abusive behaviour.

As the foregoing sections suggests, abuse is more likely to occur in what might be considered poor quality services. While research has not specifically looked at abuse in better quality services, there is a significant body of research about the factors associated with such services, where people with intellectual disability have good quality of life outcomes. Safety, emotional and physical wellbeing, are key domains of quality of life, the antithesis of abuse (Shalock et al., 2002). It is perhaps worth considering the organisational and cultural factors associated with the flip side of risk, that is better quality services that lead to quality of life outcomes for service users. A rigorous body of research demonstrates that when staff use the evidence based practice ‘Active Support’, service users have better quality of life outcomes (Bigby & Beadle-Brown, 2016a; Mansell & Beadle-Brown, 2012). Unsurprisingly, embedded in the practice of Active Support is an emphasis on staff supporting service user choice and control, engagement, communication and warm and respectful relationships. There is also growing evidence about the importance of frontline managers to the quality of staff practice, and the association between Active Support and elements of practice leadership such as, supervision, modelling, team meetings and planning the use of staff shift planning (Beadle-Brown et al., 2015; Bould et al., 2016; Clement & Bigby, 2012).

Related to the research on Active Support but adopting a different lens, Australian research has identified five dimensions of culture as common to all supported accommodation services using rigorous observational methods. Summarised in Figure 2 this work describes the positive and negative end of each of the dimensions, which are in turn associated with poor and better quality services (Bigby et al, 2014; Bigby et al., 2012; Bigby et al., 2015; Bigby & Beadle-Brown, 2016b). There are remarkable similarities, between the descriptors of quality in poorer quality services with those discussed earlier in services where abuse occurs. The five dimensions of culture identified by Bigby and colleagues provides evidence-based indicators and examples of good practices that are associated with better safety and quality of life outcome for individuals with intellectual disabilities.

In services where service users have better quality of life outcomes, culture is described as;

1. Alignment of power holder values: this dimension was characterized by strong “in action” leadership and team work. Supervisors are aligned with the espoused values of the organisation and are working alongside staff. Teamwork is emphasised and responsibility is shared by staff and supervisor, and consistently exercised by the whole team to translate espoused organisational values into practice.

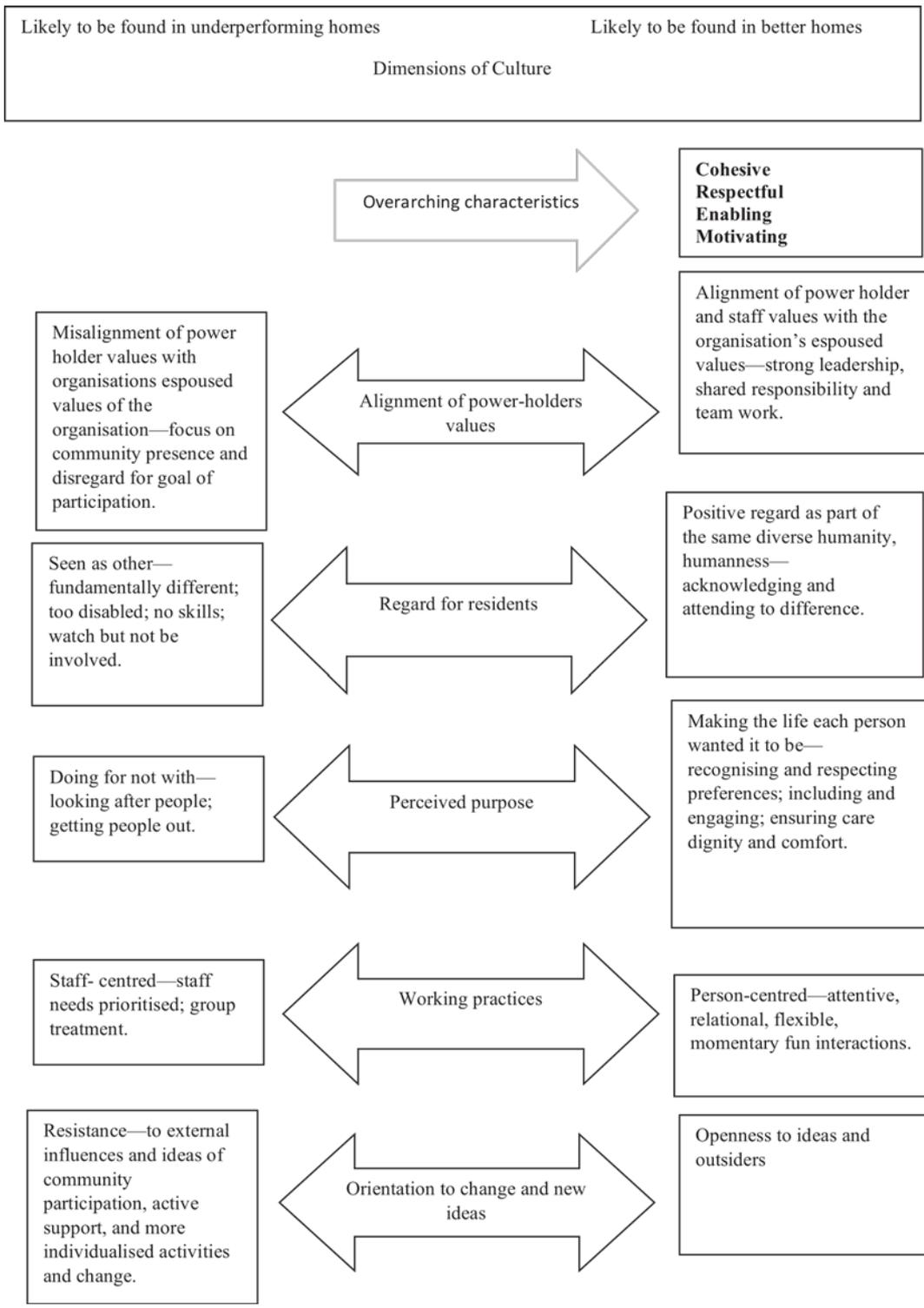


Figure 2: Culture dimensions in underperforming and better residential care

Source: Bigby & Beadle-Brown 2016a

2. Regard for residents: staff perception of residents as human, acknowledging and respecting differences in residents’ functioning and being.

3. Perceived purpose: staff perception of the overarching purpose of their practice hinged on supporting individualised practice, emphasising the residents' dignity, care, comfort and choice to lead the type of life they wanted.
4. Working practice: working practices is person centred and characterised by attentiveness, relationships, flexibility and momentary fun interactions. Clear emphasis on residents' needs and wants over completion of task and staff needs, staff are attentive to the spectrum of each residents' preferences and needs. Staff value the relationships with each resident, which are characterised by warmth, care and commitment. Also evident in this dimension was staff flexibility in their time and location - staff manage their time around the needs of residents rather than completion of task and daily routine.
5. Orientation to change and ideas: the organisation is open to outsiders and new ideas. Interaction was embraced with outsiders, such as families of residents, staff from other parts of the organisation, local communities, and communities of interest around disability issues.

Prevention of violence and abuse

Prevention can be conceptualised as investing in future outcomes by influencing current behaviours or conditions to stop negative action or behaviour, or to promote positive action or behaviour (Stagner & Lansing, 2009). Interventions should both reduce risk factors and promote protective factors, in order to successfully address abuse and ensure the health, safety and well-being of individuals with disabilities (Butchart & Mikton, 2014). Over the years Australian federal and state governments, as well as advocacy groups and other stakeholders, have developed and implemented a wide array of strategies to prevent abuse and promote safety of individuals with disabilities residing in supported accommodation.

Various models map the targets of abuse prevention (Butchart & Mikton, 2014). The most common is the World Health Organisation's three-tier prevention model (World Health Organisation [WHO], 2009; 2011; 2013). This includes primary, secondary and tertiary interventions, with each tier having different goals and strategies. This model complements the socio-ecological framework, in that every tier targets interventions at each of the four different levels of the model (individual, community, relationship and society).

- *Primary prevention*: aims to prevent abuse from occurring in the first instance; this tier includes strategies targeted at the individual, the community and the relationship level. For instance, psycho-educational intervention and behavioural skills training for people with disabilities and staff (the individual level). Primary prevention at the community and

relationship level would entail providing support, supervision and guidance for the design of services, providing adequate training, support, and supervision for staff in services, and implementing effective recruitment screening practices. At the societal level, the primary prevention tier includes efforts to promote policy and legal reform to prevent violence and abuse by challenging attitudes and social norms, challenging the unjust power relations that sustain and are sustained by violence, addressing the social conditions associated with violence, and promoting non-violent norms as well as warm and productive care relations.

- *Secondary prevention:* aims to identify and respond directly to allegations of abuse. This tier focuses on early identification and intervention, targeting those individuals at high risk of abuse and working to reduce the likelihood of its occurrence. On the individual and relationship level, secondary prevention may involve strategies that empower individuals to report abuse, training about mandatory or non-mandatory reporting by stakeholders and recognition of indicators of abuse. On the community level this tier may include effective planning of protective services, such as inspection or community visitor schemes. Finally, Secondary prevention on the societal level may include strategies for policy reforms in respect of prosecutions of offenders, enforcing criminal and civil laws as a deterrent to further abuse, enforcing disciplinary actions, and investigatory power of audit, standards or regulatory bodies.
- *Tertiary prevention:* aims to remedy any negative and harmful consequences of experiencing abuse and put in place measures to prevent its re-occurrences. On the individual level tertiary prevention includes efforts to provide medical, psychological and social supports for abuse victims, as well as peer support counselling and rehabilitation for perpetrators. On the community level, it may include ongoing evaluation and monitoring of organisational procedures and culture in services in which abuse has occurred, and implementing policies to better respond and assist victims of abuse.

Over the last two decades abuse against people with intellectual disabilities has gained significant attention from governments, the media, advocacy and the disability sector. A sequence of reports has inquired into abuse in the lives of people with disabilities, the state of disability service systems, and made recommendations for prevention strategies and policy reform. For example, a comprehensive review of models of abuse prevention strategies was undertaken in 2001 in a report commissioned by National Disability Administrators on behalf of Commonwealth, State and Territory Ministers responsible for disability services in Australia (National Disability Administrators, 2002). This was followed up by National Disability Services in a further report in 2002 and later the Zero Tolerance

project in 2016 (NDS, 2016). At the Commonwealth level, in 2015 a Senate Standing Committee on Community Affairs investigated allegations of abuse in the disability sector which led to calls from disability advocates for a Royal Commission into abuse of people with disabilities (Senate Community Affairs Committee Secretariat, 2015). At the State level the Office of the Public Advocate and Victorian Ombudsman have prepared reports (Victorian Ombudsman, 2015) and most recently the Family and Community Development Committee of the Victorian Parliament conducted an inquiry into the abuse in disability services (Parliament of Victoria, 2016).

Service standards and procedural guidelines for prevention, responding and reporting abuse and neglect have been developed by federal and state government departments responsible for the funding and monitoring of disability services. While there are national standards for disability services, monitoring and other regulatory mechanisms differ in each jurisdiction, making it difficult to gain an overall picture. This is likely to change with the full roll out of the National Disability Insurance (NDIS) scheme in 2020 and development of a national quality and safeguarding framework. However, in most jurisdictions disability service providers are regularly audited against the Standards, and receive clear information to guide the development of their own service-specific policies and procedures. Such policies generally follow a similar framework addressing the three tiers of prevention but tend to focus on managerial compliance to procedures and paperwork with little attention to direct observation or evaluation of care practices (McEwan et al., 2014). It has been suggested that this approach may shift the focus of attention from individual outcomes (such as protection from abuse) to compliance, prioritising the management of systems over the meeting of individual need (Di Rita et al., 2008; Goggin & Newell, 2005; Robinson, 2013; Robinson & Chenoweth, 2011; 2012).

In the current era policy makers, advocates, funders and other stakeholders have recognised the need to conduct rigorous evaluation of abuse prevention strategies in order to establish the effectiveness and to advance evidence-based practice in this field (Northway et al., 2007; Perry, 2004; Quarmby, 2011; Robinson & Chenoweth, 2011; 2012).

Evaluation of prevention strategies

Evaluation allows the effectiveness of intervention strategies to be measured, and is important for determining whether an intervention is of benefit to participants (Holzer et al., 2006). It may provide evidence for promoting “evidence-based practice” that will be increasingly required by the NDIS and be useful for service planners, practitioners and policy-makers in making decisions about public policy and program funding.

Evaluation type

The three main types of evaluation are concerned with process, impact or outcome (Tomison, 2000).

- Process evaluation: explores features of the intervention such as the nature of the service offered, who is participating and who is facilitating the intervention (Hall, 2009). This type of evaluation may identify areas where change is needed to enhance service delivery.
- Impact evaluation: measures whether an intervention has an effect on participants as envisaged by its aims and objectives. For example, an impact evaluation of an abuse education intervention would assess whether participants' knowledge had increased as a result of participating in the program.
- Outcome evaluation: assesses the long-term effectiveness of a program of intervention.

The difference between an impact and an outcome evaluation is that an impact evaluation looks at direct or immediate aims of an intervention, such as improving knowledge or skills, whereas an outcome evaluation considers the underlying goals, such as reduced incidence and prevalence of abuse in accommodation services (Holzer et al., 2006; Holzer, 2007).

In the following section, we describe the method and findings of a systematic scoping review of the national and international literature on the evaluation of abuse prevention strategies.

Systematic scoping review of abuse prevention interventions

Method

Scoping reviews provide a systematic method for mapping the breadth of existing research literature on an emerging topic of interest where high quality evidence may be limited (Arksey & O'Malley, 2005; McKinstry et al., 2014). To identify relevant studies in the area of abuse prevention interventions, a systematic search was undertaken of seven databases; MEDLINE, ProQuest Social Science and Humanities, PsychInfo, Social Services Abstracts, Sociological Abstracts and Google Scholar. The search used the various terms that refer to intellectual disability: learning disability, developmental disability, cognitive impairment and mental retardation; the research phenomena: sexual abuse, psychological abuse, financial abuse, service abuse, physical abuse, abuse, violence, assault; and prevention strategies: prevention, intervention, training, services.

Inclusion criteria were that an article met the following criteria:

- Published between January 2007 to 2017
- Published in English.
- Included adult participants (18 years or older)

- Included original empirical data
- Included a detailed description of abuse prevention intervention for people with intellectual disability.

Abstracts (and, in some instances, full articles) were reviewed to select original studies describing and evaluating abuse prevention strategies for people with intellectual disabilities. In addition, citations within key papers were inspected, and a hand-search was undertaken of relevant peer-reviewed journals not included in the database search (*Disability and Society*, *Journal of Interpersonal Violence*, and *Child Abuse and Neglect*). Finally, a search was conducted for grey literature and research reports.

As Figure 3 shows a total of 141 articles were identified by title and abstract. A close reading of these reduced the overall pool to 136. After careful reading of each abstract, 109 articles were excluded as they did not meet the inclusion criteria, and 26 were discarded as either not original research, having a primary focus on children or adolescents or not relevant to the research question. The remaining 6 papers which are summarised in Table 1, met the required criteria. The context of each paper was summarised, and data extracted from each included study on number and characteristics of participants in the intervention and control groups (if available); type of abuse or violence it aimed to prevent; type of intervention (method of delivery; content), study design and outcomes evaluation.

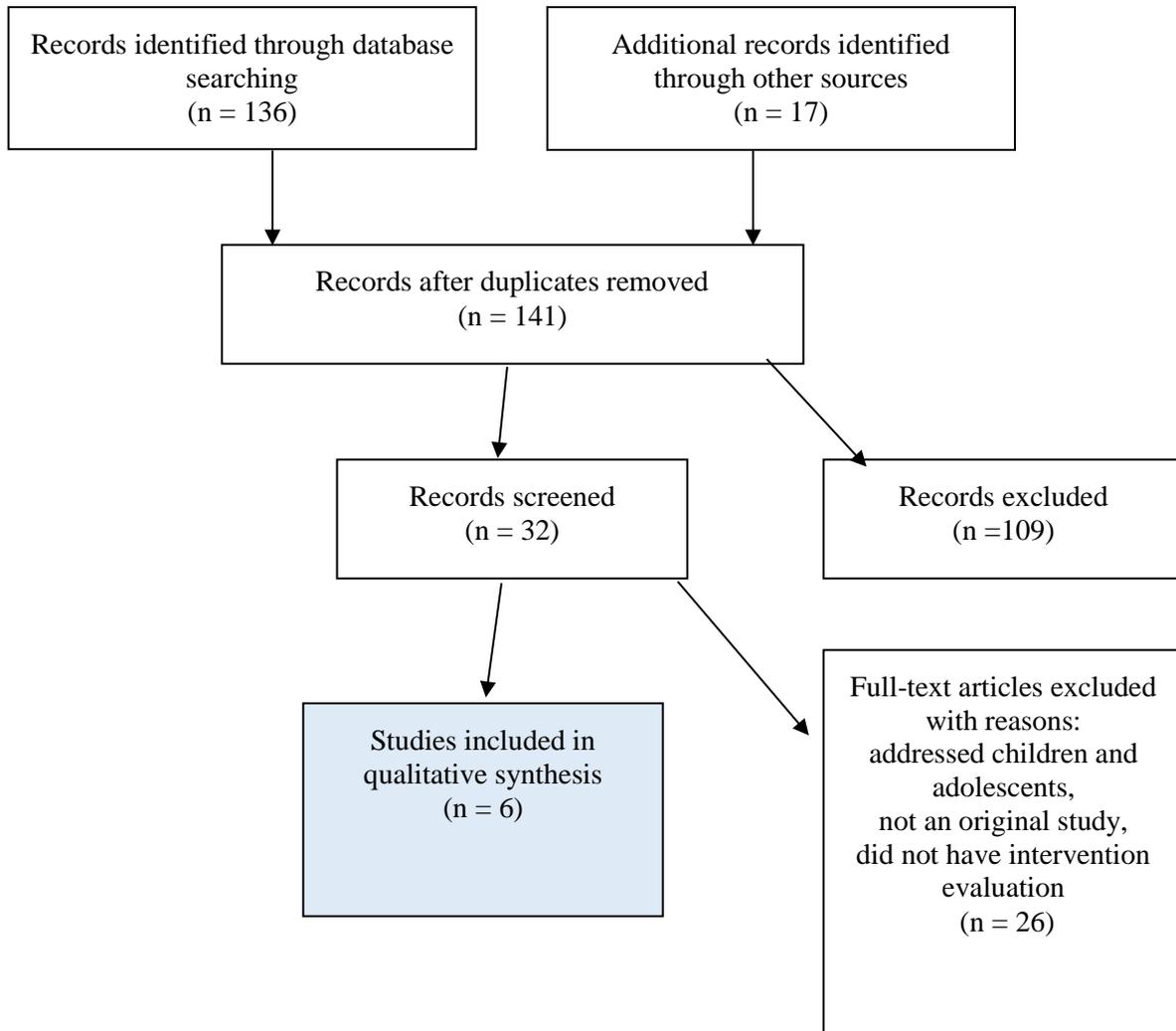


Figure 3: Flow diagram of search processes

Table 1.

Authors	Sample	Type of abuse	Intervention	Study design	Outcome
<p><u>Behavioural skills training</u></p> <p>Egemo-Helm, Miltenberger, Knudson, Finstrom, Jostad & Johnson (2007).</p>	Four women with mild to moderate intellectual disability.	Sexual abuse	Three one hour training sessions to increase recognition and response to sexual abuse situations. Rehearsal of appropriate responses and in-situ assessment.	Single-subject	Participants showed improvement in recognizing and responding to abuse situation in role-plays. However, the skills failed to generalise to in-situ assessments until the situ training was implemented
<p><u>Training based on cognitively orientated decision approach.</u></p> <p>Hickson, Khemka, Golden & Chatzistyli (2015).</p>	<p>58 men and women with mild intellectual disability.</p> <p>30 in the intervention group and 28 in the control group.</p>	Sexual, physical, and verbal (psychological) abuse	<p>12 small-group instructional sessions with ESCAPE-DD.</p> <p>The curriculum addressed cognitive, motivational and emotional components of recognizing and reacting to the abuse and processes involved in effective decision-making and empowerment.</p>	Randomised control trial	Participants who experienced ESCAPE-DD demonstrated significant improvement in overall effective decision making, were able to recognise abusive situation, seek help and to avoid the situation compared to the control. No effect of the intervention was found on abuse awareness measures.
<p><u>Psycho-education</u></p>	Not reported	Financial, sexual,	A one-session abuse	Participatory	The participants reported greater

Authors	Sample	Type of abuse	Intervention	Study design	Outcome
<p><u>training for- individuals with intellectual disabilities</u></p> <p>Lund, & Hammond (2014).</p>		physical and verbal abuse	psycho-education program. The ‘Stopping Abuse for Everyone’ (SAFE) curriculum: contents covered definitions of abuse and how to report abuse.	action research	knowledge of abuse. However, an evaluation of these reports was not conducted.
Bowman, Scotti & Morris (2010).	124 service providers (direct care staff and supervisors), working in day care centres and residential group home settings	Sexual abuse	Four hours of training in: (a) The definition of sexual abuse; (b) Sexual abuse risk factors and patterns for abuse among individuals with intellectual disability; c) Information on HIV/AIDS; d) Identifying and responding to suspected sexual abuse.	Cohort (pre- and post-intervention with no control group)	Slight improvement in knowledge and attitudes about sexual abuse and the sexuality of persons with intellectual disability were found, no change was found in staffs’ general attitude toward individuals with intellectual disability.
Peckham, Howlett & Corbett (2007).	Seven women with significant intellectual disability who had been victims of sexual abuse and their seven professional care staff	Sexual abuse	20 sessions of survivor group for the women with intellectual disability targeted to build trust and rapport, and help reprocess the trauma	Repeated-measures design (double baseline, mid-treatment, post-treatment and follow up)	Women with intellectual disability showed improvements in sexual knowledge, reduced trauma and depression. Carers demonstrated improved knowledge and awareness of sexual abuse of women with intellectual disability.

Authors	Sample	Type of abuse	Intervention	Study design	Outcome
			of their sexual abuse. Educational support group for their carers, aimed to provide knowledge about sexual abuse.		
Bollman, Davis, & Zarcone (2009).	Two women with mild intellectual disabilities who lived at a state-operated residential facility	Inappropriate staff interaction in the context of physical sexual and verbal abuse	96 video scenarios: 48 presented appropriate and 48 inappropriate interactions with staff. After the presentation of each scenario the participants were asked to act out how they would react. When the participant responded to the situation, the observer used a 12-step task analysis to score performance.	Cohort (pre- and post-intervention with no control group)	The reporting skill included making a self-advocacy response, walking away, and reporting the interaction. Participants' performance was measured during baseline, post-testing, 2- and 4-week intervals. Participants learned reporting skills, maintained these skills at 2- and 4-week follow-up, and generalized the skills to novel stimulus situations.

Analysis

The systematic search for evaluations of the effectiveness of interventions to prevent abuse against persons with intellectual disabilities identified six studies that met the inclusion criteria. Three of them evaluated interventions that were specifically designed to prevent sexual abuse and three broadly addressed various forms of violence and abuse.

Half of the intervention programs targeted women with intellectual disabilities, focusing mainly on promoting safety, knowledge and skills related to sexuality (Bollman et al., 2009; Egemo-Helm et al., 2007; Peckham et al., 2007). Interestingly, despite the fact that prevalence studies suggest that most incidents of abuse of people with intellectual disability occur within the disability service systems and care relationships, only one program specifically addressed the issue of abuse in the context of care services (Bollman et al., 2009). All but one were primary prevention strategies targeting the individual level and included a small sample of participants with mild to moderate intellectual disability, where most participants had relatively good communication skills. Egemo-Helm et al. (2007) explicitly noted the relatively competent level of their participants' communication skills, using terms such as 'good', 'adequate' and 'sufficient'.

In most cases evaluations were quantitative and focused on measuring changes to knowledge, attitude and behaviour through use of role-play, vignettes or in-situ situations. While some studies evaluated the outcome maintenance using follow-up evaluation (up to three months), none monitored the longer-term impact and maintenance of the outcomes over time. Moreover, none of the studies aimed to generalise skills and thus failed to establish that the training programs evaluated were effective in preventing violence and abuse in the real world. The studies summarised in Table 1 can be categorised into three groups based on method of training and target population:

- a) Behavioural-skills training (Egemo-Helm et al., 2007)
- b) Training using a cognitively oriented, decision-making approach (Hickson et al., 2015).
- c) Psycho-education training for care staff and or individuals with intellectual disabilities (Bollman et al. 2009; Bowman et al., 2010; Lund & Hammond, 2014; Peckham et al., 2007).

To provide a greater understanding of the assessment, training, and testing tactics used in these six studies, a representative one from category is described:

Behavioural - skills training

Egemo-Helm et al. (2007) employed behavioural-skills training of appropriate recognition and response to sexual abuse situations.

Intervention: three one hour training sessions were designed to increase participants awareness of sexual abuse situations and promote an effective response. This was defined as saying ‘no’ or verbally refusing, leaving a situation or telling the other person to leave, and reporting the incident to a trusted staff member. Trainers briefly discussed private body parts, described the difference between a sexual abuse situation and an innocuous situation, described appropriate and inappropriate relationships, and identified examples of each. The trainers described and modelled the appropriate behaviours for the participants. The participants actively rehearsed the correct responses in role-plays of sexual solicitations with the trainers, and received praise for correct performance of the skills and corrective feedback as needed. Training continued until the participants demonstrated the safety skills in response to all of the lures in role-play scenarios without assistance.

Researchers conducted an in-situ assessment for each participant within a week of the third training session. The assessment evaluated behaviour in a natural setting when participants were unaware they were being assessed. They were approached by a confederate, in a location such as a park or front yard, who presented an abduction lure. If the participant failed to respond with the desired behaviour, in-situ training was immediately implemented. The trainer then described and modelled the correct response in that scenario. After modelling, the trainer instructed the participant to rehearse the scenario a number of times until they performed the correct responses in at least five consecutive role-plays.

Evaluation of the intervention: an across subject design was employed. Seven women with mild intellectual disabilities participated in the skills training program. Their responses to self-report knowledge, role-plays, vignettes and in-situ assessments were evaluated using the same measures, before and three weeks, one month and three months following the completion of the training.

Research findings: Four women completed both the intervention and assessment. The assessment revealed increased presentation of safety skills and maintenance of knowledge and skills. However, the amount of in-situ training varied widely among the four participants suggesting that interventions with individuals with intellectual disability need to be individually tailored to each participants’ ability. However, it should be noted that, due to discomfort with the in-situ training only 4 of the 7 women completed the intervention. This suggests that this type of training may pose risks of psychological harm to individuals with intellectual disabilities by exposing them to demonstrations of abusive situations, and participants need to be closely monitored for signs of psychological distress during the intervention period (Barger et al., 2009; Doughty et al., 2010).

Training based on a cognitively oriented, decision-making approach

Hickson et al., (2015) evaluated the effectiveness of ESCAPE-DD (An Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment) to assess its impact on the decision-making skills of adults with intellectual disabilities in hypothetical situations of sexual, physical or psychological abuse. The curriculum aimed to teach effective decision-making strategies to individuals with mild to moderate intellectual disabilities, for them to recognise and appropriately respond to a wide array of abuse situations in which the perpetrator of the abuse is someone familiar to the person.

Intervention: 12 small-group instructional sessions employing the ESCAPE-DD curriculum. The ESCAPE-DD intervention includes two units addressing the interplay between cognitive, motivational and emotional process involved in decision-making (Hickson et al., 2013; 2015; Khemka et al., 2005).

Unit 1, comprising the first five lessons, was designed to teach key concepts of abuse as a basis for identifying sexual, physical, and verbal abuse situations that might require reasoned, deliberative decision making to avoid or escape from. It aimed to establish the importance of always considering three self-protective goals in decision making about abusive situations; be independent, be safe now, and be safe later.

Unit 2, comprising the remaining seven lessons, aimed to model and provide guided practice in the application of a four-step decision-making strategy to hypothetical situations involving abuse: identify the problem, generate alternatives, evaluate possible consequences of each alternative in terms of the three established goals, and select the best course of action for the situation.

Evaluation of the intervention: a randomised control research design was employed to evaluate the outcome. Fifty-eight individuals with intellectual disability were randomly assigned either to an intervention (n=28) or control group (n=30). All participants completed the decision-making scale at pre-test and post-test. A scale developed for the study (Hickson et al., 2015) provided a measure of decision making in hypothetical situations of abuse. It consisted of six brief vignettes in which a protagonist was faced with a situation involving sexual, physical, or verbal abuse in a home or workplace setting. Each vignette was presented to the individual and followed by two questions; 1) what is happening in this story? This was intended to assess problem awareness, the individual's ability to articulate the problem in the vignette situation, and; 2) what should (name of the protagonist) do? This was intended to assess decision-making effectiveness.

Responses to the problem-awareness question were coded as yes if they reflected an identification of abusive situations and no for all other responses. Responses to the decision-making question were coded as indicative of overall effective decision making if they reflected either an attempt to seek safety now and/or later through independent action or by seeking help.

Research Findings: Participation in the ESCAPE-DD curriculum intervention was shown to be associated with increased application of effective decision-making skills in response to scenarios involving sexual, physical, and verbal abuse. Individuals with intellectual disability who received ESCAPE-DD increased their overall effective decision-making scores and their safe-now effective decision-making scores significantly more than the control group. However, it is important to note the outcome was assessed immediately after the intervention using the same methods as the training. There was no evidence that the participants were able to transfer their knowledge to real life situations and whether the knowledge and acquired skills were maintained over time.

Staff educational training

Bowman and colleagues (2010) developed and evaluated educational workshops designed for direct care service providers in the field of intellectual disabilities. The four-hour workshop included information, didactic instruction and group activities aimed to increase staff knowledge and awareness of sexual abuse of individuals with intellectual disability, promote the perspective that individuals with intellectual disability are sexual beings and facilitate positive attitudes towards the sexuality of individuals with intellectual disability

Intervention: the four hour workshop included information on; the definition of sexual abuse, including state reporting laws relevant to children and adults; sexual abuse risk factors and patterns for people with developmental disabilities; HIV and AIDS information; how to identify physical and behavioural signs of sexual abuse; sexual abuse prevention strategies; factors that contribute to sexual abuse; changing negative attitudes that contribute to abuse; an overview of curricular and instructional packages for teaching AIDS education, sexuality education, and sexual abuse prevention; and, how to build safer environments.

Evaluation: a cohort design was employed, 124 direct care, supervisors and other service providers from residential group homes and day treatment program settings were assessed on sexual abuse knowledge before and after undergoing the workshop with two research tools: The Sexual Abuse Attitudes Knowledge Questionnaire (SAAKQ); and the Global Perceptions Scale (GPS).

Research Findings: staff knowledge of factors related to sexual abuse and attitudes about sexual abuse and sexuality among individuals with intellectual disabilities increased as a result of their

participation in the workshop. There were no differences in general attitudes towards sexuality of individuals with intellectual disabilities. No follow-up or maintenance evaluation was conducted.

Discussion

A public health approach is useful for assessing the state of the research evidence in the area of abuse prevention for individuals with intellectual disabilities. According to this perspective, efforts to develop effective prevention strategies should include the following steps:

- Defining what constitutes abuse among individuals with intellectual disabilities, and its consequences, conceptually and numerically.
- Identifying risk and protective factors for abuse that might be modifiable through intervention. In this step, it is crucial to address the multilevel factors and interactions in the levels of the socio-ecological model.
- Developing and testing prevention strategies in order to develop evidence-based practice to build and evaluate strategies based both on research and practice, as well as on the lived experiences and perceptions of various stakeholders (individuals with disabilities, carers, policymakers and professionals). Once a strategy or an intervention is implemented, its effectiveness should be determined by outcome evaluations.
- Scaling up effective interventions, disseminating knowledge about them, and assessing cost and cost-effectiveness (Krug et al., 2002).

Drawing from this framework the evidence gap in research and evidence-based practice is apparent. The current knowledge of the incidence and impact of abuse among individuals with intellectual disabilities is limited; the national and international literature reports a wide range of statistics on the prevalence (Mikton & Shakespeare, 2014; Mikton et al., 2014). Development of knowledge is hampered by methodological weaknesses and inconsistent definitions of disability and abuse. This population is rarely included in national epidemiological representative samples or population studies of violence and abuse. Furthermore, it is widely acknowledged that current data underestimate the prevalence of abuse among individuals with profound intellectual disabilities, those living in group homes or those with communication difficulties (Mikton & Shakespeare, 2014; Mikton et al., 2014). To begin to address these gaps in the evidence, high quality epidemiological research is needed that uses standardised definitions and inclusive methods.

In Victoria, the Disability Services Commissioner (DSC) collects information on complaints in regard to people with a disability as well as in regard to category 1 incidents relating to staff to client assault, unexplained injury, client to client assault and poor quality care. In addition, as part of the process of reviewing category 1 incidents the DSC reviews incident reports and quality of support

reviews completed by the Department of Health and Human Services (DHHS). These data may provide a valuable and unique opportunity to study incidents of abuse and by doing so obtain a greater understanding of this issue.

While there is some anecdotal data of risk factors for abuse among individuals with mild intellectual disability, there is very little in respect of individuals with severe intellectual disabilities and communication difficulties. As it is suggested this latter group are at greater risk of abuse, and their safety needs and skills are often overlooked by research and practice it will be important to explore, identify and address specific risks and protective factors in their lives. Finally, while many abuse prevention programs are described in the scholarly and grey literature only a very small proportion have been evaluated, and these all relate to primary prevention strategies predominantly targeted at individuals with mild to moderate intellectual disability. This literature review has demonstrated the limited evidence about the effectiveness of programs to prevent abuse against individuals with intellectual disability. There are no evaluations of the cost effectiveness of existing prevention strategies, and evidence is wholly lacking on successfully scaling up programs and evaluating their costs and benefits.

Despite using broad inclusion criterion, our systematic literature review, encompassing national and international manuscripts published on the evaluation of prevention intervention for individuals with intellectual disabilities, identified only six articles reporting effectiveness studies. Our review reveals that although the notion of prevention strategies has been discussed in the peer-reviewed and grey literature, and many interventions have been designed and implemented over the years, only a few interventions have been evaluated. All of these evaluations involved a small number of participants and investigated specific impact over short periods of time rather than longer term outcomes. Moreover, all the evaluated interventions were primary interventions, targeting the individual level on the socio-ecological model.

All evaluated interventions were based on the assumption that adults with intellectual disability can be taught skills that will aid them in preventing or protecting themselves from abuse. The outcome measures of interventions were specific changes to knowledge, attitudes or behaviour demonstrate through role-plays and in-situ training. None of the studies evaluated the effectiveness of interventions in reducing the prevalence of actual abuse. The findings of these studies demonstrated that indeed individuals with mild to moderate intellectual disability may successfully acquire knowledge or skills to assist them with recognising an abusive situation and responding in an effective way. Nevertheless, research suggests that such knowledge and skills are not necessarily transferable and the ability to demonstrate certain behavioural responses in a role-play may not

transfer to behaviour shown during in-situ assessment or be indicative of the person's ability to respond effectively in a real situation. None of interventions have addressed the broader context and evaluated long-term effectiveness in reducing the prevalence of violence and abuse for individuals with intellectual disabilities. Moreover, it is concerning that none of the interventions reviewed were designed to include individuals with severe or profound intellectual disability or with communication difficulties. This may be attributed to the verbally mediated teaching methods and skills assessments that were used in these interventions (Doughty & Kane, 2010).

The safety and quality of life outcomes of people with severe intellectual disability are dependent on the quality of support, and inextricably connected to staff practices. It appears that the kinds of intervention strategies evaluated to date are not appropriate for many people with severe intellectual disabilities.

Finally, some scholars have identified that to ensure skills maintenance, the environments in which individuals with intellectual disabilities live should be considered (Marsland et al., 2007; Robinson, 2013; Robinson & Chenoweth, 2011; 2012). Most of the interventions reviewed involved a preventative measure that required the person with intellectual disability to report an abusive situation to someone else. This type of disclosure is much more likely if the person has a positive and trusting relationship with staff or caregivers. Some of the prevention and protection training reviewed runs the danger of placing participants in difficult positions, if they do not have this type of relationship with staff and their experiences of everyday environments conflict with those discussed in training sessions.

Taking a holistic view of the body of evidence reported in the scholarly literature, it seems that despite the growing recognition of the need to lay out comprehensive prevention strategies incorporating primary, secondary and tertiary interventions, and targeting individuals with intellectual disabilities in policy reform, no evaluation of outcomes has been conducted. Therefore, it remains to be established whether the incidence, experience and responses to abuse have been affected by these interventions and strategies (Marsland et al., 2007; Robinson & Chenoweth, 2005; 2012; Mandeville & Hanson, 2000).

It seems that in order to establish "evidence-based" effective prevention strategies and to reduce the prevalence of abuse and violence in the lives of people with intellectual disabilities, research and interventions need to evolve from the response-to-risk approach to a broader framework encompassing individual's safety as part of their quality of life.

In the current Australian context where most people with intellectual disabilities are receiving support from the disability services system, it is apparent that any prevention strategy should address the nature and quality of support services generally and supported accommodation services particularly.

Organisational culture is a fundamental feature repeatedly identified as a key risk or protective factor associated with abuse of individuals with intellectual disability in residential care (Marsland et al., 2007). Earlier in this report we briefly outlined the staff and managerial practices associated with good quality of life outcomes in supported accommodation services, and the characteristics of culture in poor or abusive services and those of better quality services (see Bigby & Beadle-Brown, 2016a & b). Given this body of evidence, several authors have stressed the importance of moving away from what they identify as being primarily "procedural" or "managerial" responses to incidents of abuse in services. Instead they suggest the importance of building strategies that focus on changes to the culture and practice of services, promoting "protective cultures" that have been proven to promote the fulfilment of human rights, quality of life and safeguarding for people with disabilities (Mandeville & Hanson, 2000; Marsland et al., 2007; Robinson & Chenoweth, 2011; 2012).

Knowledge about culture in supported accommodation services developed from a program of rigorous research by Bigby and colleagues has the potential to inform quality assessment frameworks, staff training and the organisational structures and processes used by disability service organisations. Understanding the nature of culture provides, for example, a set of descriptors that could be used to develop information and observational tools for consumers, funders and regulators to support judgements and comparison of residential services. The dimensions can also be used to develop a measure of quality that could be used in service monitoring, research and service evaluation.

In congruence with the socio-ecological model, the evidence suggests that dimensions of culture are not linear, as the different elements are mutually reinforcing. There is mutual interaction between the different dimensions of culture, for example, the values of the power-holders, regard for residents, perceived purpose of staff work, working practices, and orientation to change. This knowledge provides a framework that pinpoints where action might be directed to bring about cultural change and suggests that intervention targeted at any one dimension will influence the other.

Using this understanding in designing broad prevention programs may guide the observation, judgment and evaluation of supported accommodation by stakeholders such as community visitors, funders, advocates and family members. For instance, a guide to visiting based on these indicators

has already been adopted by the Victoria community visitor program (Bigby & Bould, 2014). A research instrument to evaluate group home culture, the Group Home Culture Scale, is currently being developed and evaluated (Humphreys et al., 2016)

This approach may also help to design the training and education of front line managers, support workers and people with disabilities. It seems that rather than providing staff with targeted training on abuse and prevention a better approach might be to incorporate this knowledge into ongoing training and support designed to ensure quality services and promote quality of life, well-being and human rights of residents (Robinson, 2013; Robinson & Chenoweth 2011; 2012).

To conclude, our review of evidence in regards to risk and protective factors of abuse among individuals with intellectual disability identifies the paucity of evidence-based prevention strategies. It suggests that the dimensions of culture in supported accommodation services recognised by Bigby and colleagues provide evidence-based indicators and examples of good practices that are associated with better safety and quality of life outcome for individuals with intellectual disabilities in these services.

References

- Anda, R. F., Felitti, V. J., Bremner, J. D., Walker, J. D., Whitfield, C. H., Perry, B. D., & Giles, W. H. (2006). The enduring effects of abuse and related adverse experiences in childhood. *European Archives of Psychiatry and Clinical Neuroscience*, 256(3), 174-186.
- Arksey, H. & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Beadle-Brown, J., Bigby, C., & Bould, E. (2015). Observing practice leadership in intellectual and developmental disability services. *Journal of Intellectual Disability Research*, 59(12), 1081–1093. Doi: 10.1111/jir.12208
- Beadle-Brown, J., Mansell, J., Cambridge, P., Milne, A. & Whelton, B. (2010). Adult protection of people with intellectual disabilities: incidence, nature and responses. *Journal of Applied Research in Intellectual Disabilities*, 23(6), 573-584.
- Bigby, C., & Beadle-Brown, J. (2016a). Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference? *Journal of Applied Research in Intellectual Disabilities*. Doi: 10.1111/jar.12291/full
- Bigby, C., & Beadle-Brown, J. (2016b) Culture in better group homes for people with severe and profound intellectual disability. *Intellectual and Developmental Disabilities*, 54, 316-331. _Doi: 10.1352/1934-9556-54.5.316
- Bigby, C., Knox, M., Beadle Brown, J., & Bould, E. (2014). Identifying good group homes for people with severe intellectual disability: Qualitative indicators using a quality of life framework. *Intellectual and Developmental Disability*, 52(5), 348-366. doi: 10.1352/1934-9556-.5.348 <http://hdl.handle.net/1959.9/553198>
- Bigby, C. & Bould, E. (2014). *Guide to visiting and good group homes*. Melbourne, Australia: Living with Disability Research Centre, La Trobe University.
- Bigby, C., Knox, M., Beadle-Brown, J., & Clement. T. (2015). ‘We just call them people’: Positive regard for people with severe intellectual disability who live in of group homes. *Journal of Applied Research in Intellectual Disability*, 28, 283–295.
- Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., & Mansell., J. (2012). Uncovering dimensions of informal culture in underperforming group homes for people with severe intellectual disabilities. *Intellectual and Developmental Disabilities*, 50(6), 452–467.
- Blum, R. W., Kelly, A., & Ireland, M. (2001). Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *Journal of Adolescent Health*, 28(6), 481-490.

- Bollman, J. R. & Davis, P. K. (2009). Teaching women with intellectual disabilities to identify and report inappropriate staff-to-resident interactions. *Journal of Applied Behavior Analysis, 42*, 813–817. Doi: 10.1901/jaba.2009.42-813
- Bould, E., Beadle-Brown, J., Bigby, C., & Iacono, T. (2016). The role of practice leadership in active support: impact of practice leaders' presence in services. *International Journal of Developmental Disabilities. Doi: 10.1080/20473869.2016.1229524*
- Bowman, R. A., Scotti, J. R., & Morris, T. L. (2010). Sexual abuse prevention: A training program for developmental disabilities service providers. *Journal of Child Sexual Abuse, 19*(2), 119-127.
- Brown, H., Stein, J., & Turk, V. (1995). The sexual abuse of adults with learning disabilities: A second incidence survey. *Mental Handicap Research, 8*, 3–23.
- Butchart, A. & Mikton, C. (2014). *Global status report on violence prevention, 2014. Technical Report*. Retrieved from: <http://eprints.uwe.ac.uk/30034>
- Cambridge, P. (1998). The physical abuse of people with learning disabilities and challenging behaviours: lessons for commissioners and providers. *Tizard Learning Disability Review, 3*(1), 18-26.
- Cambridge, P., Beadle-Brown, J., Milne, A., Mansell, J., & Whelton, B. (2011). Patterns of risk in adult protection referrals for sexual abuse and people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 24*(2), 118-132.
- Cashmore, J.; Dolby, R.; Brennan, D. & the NSW Child Protection Council's Systems Abuse Committee. (1994). *Systems Abuse: Problems and Solutions*. Sydney, Australia: NSW Child Protection Council.
- Casteel C., Martin S. L., Smith J. B., Gurka K. K., & Kupper L. L. (2008). National study of physical and sexual assault among women with disabilities. *Injury Prevention, 14*, 87–90.
- Charter of Human Rights and Responsibilities Act 2006 (Vic). Retrieved from http://www.austlii.edu.au/cgi-bin/viewdb/au/legis/vic/consol_act/cohrara2006433/
- Clement, T., & Bigby, C. (2012). Competencies of frontline managers of supported accommodation services: Issues for practice and future research. *Journal of Intellectual and Developmental Disability, 37*, 131-140.
- Cooper, C., Selwood, A., & Livingston, G. (2008). The prevalence of elder abuse and neglect: a systematic review. *Age and ageing, 37*(2), 151-160.

Department of Communities. (2012). *Preventing and responding to the abuse, neglect and exploitation of people with a disability: Tips and resources for disability service managers and staff*. Brisbane, Australia: Queensland Government.

Department of Health. (2011). *Government Policy on Adult Safeguarding United Kingdom*. Retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126748

Department of Human Services. (2005). *Responding to allegations of physical or sexual assault: Departmental instruction August 2005*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2007). *Understanding the Quality Framework for Disability Services in Victoria: A resource guide for disability service providers*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2009). *Critical Incident Response Management (CIRM) Service Guidelines*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2009). *Residential services practice manual*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2010). *Incident reporting instruction—technical update December 2010*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2010). *Protocol between Victoria Police and the Department of Human Services: reporting employee criminal conduct policy*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2011). *Critical Client Incident Management Instruction*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2011). *Department of Human Services Standards (June 2011)*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2011). *Departmental Incident reporting guide*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Human Services. (2012). *Department of Human Services Standards evidence guide (December 2011)*. Melbourne, Australia: Victorian Government Department of Human Services.

Department of Social Services. (2016). *Do you need to report abuse or neglect of people with disability*. Retrieved from <https://www.jobaccess.gov.au/people-with-disability/do-you-need-report-abuse-or-neglect-people-with-disability>

Didi, A., Soldatic, K., Frohmader, C., & Dowse, L. (2016). Violence against women with disabilities: Is Australia meeting its human rights obligations? *Australian Journal of Human Rights*, 22(1), 159-177.

DiRita, P. A., Parmenter, T. R., & Stancliffe, R. J. (2008). Utility, Economic Rationalism and the Circumscription of Agency. *Journal of Intellectual Disability Research*, 52(7), 618–625.

Disability Services Act, 2006 (Vic). Available from www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.../06-023a.pdf

Disability Services Commissioner. (2008). *Disability Service Commissioner Annual Report 2008*. Melbourne, Australia: Victorian Government Office of the Disability Services Commissioner.

Disability Services Commissioner. (2009). *Disability Service Commissioner Annual Report 2009*. Melbourne, Australia: Victorian Government Office of the Disability Services Commissioner.

Disability Services Commissioner. (2010). *Disability Service Commissioner Annual Report 2010*. Melbourne, Australia: Victorian Government Office of the Disability Services Commissioner.

Disability Services Commissioner. (2011). *Disability Service Commissioner Annual Report 2011*. Melbourne, Australia: Victorian Government Office of the Disability Services Commissioner.

Doughty, A. H., & Kane, L. M. (2010). Teaching abuse-protection skills to people with intellectual disabilities: A review of the literature. *Research in developmental disabilities*, 31(2), 331-337.

Dowse, L., Soldatic, K., Didi, A., Frohmader, C., & van Toorn, G. (2013). *Stop the Violence: Addressing Violence Against Women and Girls with Disabilities in Australia: Background paper*. Retrieved from http://wwda.org.au/wp-content/uploads/2013/12/STV_Background_Paper_FINAL.pdf

Egemo-Helm, K. R., Miltenberger, R. G., Knudson, P., Finstrom, N., Jostad, C., & Johnson, B. (2007). An evaluation of in-situ training to teach sexual abuse prevention skills to women with mental retardation. *Behavioral Interventions*, 22(2), 99-119.

Fawcett, B. (2009). Vulnerability: questioning the certainties in social work and health. *International Social Work*, 52(4), 473-484.

Felce, D., Lowe, K. & Jones, E. (2002). Staff activity in supported housing services. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 388–403. Doi: 10.1046/j.1468-3148.2002.00130.x

Fisher, M. H., Baird, J. V., Currey, A. D., & Hodapp, R. M. (2016). Victimization and social vulnerability of adults with intellectual disability: a review of research extending beyond Wilson and Brewer. *Australian Psychologist*, 51(2), 114-127.

Fitzsimons, N. M. (2017). Partnering with People with Disabilities to Prevent Interpersonal Violence: Organization Practices Grounded in the Social Model of Disability and Spectrum of Prevention. In A. J. Johnson, J. R. Nelson & E. M. Lund (Eds.), *Religion, Disability, and Interpersonal Violence* (pp. 45-65). Cham, Switzerland: Springer.

Gilson S. F., DePoy E., & Cramer E. P. (2001). Linking the assessment of self-reported functional capacity with abuse experiences of women with disabilities. *Violence Against Women*, 7, 418–431.

Goggin, G., & Newell, C. (2005). *Disability in Australia: Exposing a social apartheid*. Sydney, Australia: UNSW Press.

Gray-Stanley, J. A., & Muramatsu, N. (2011). Work stress, burnout, and social and personal resources among direct care workers. *Research in developmental disabilities*, 32(3), 1065-1074.

Hall, R. (2009). Evaluation principles and practice. In G. Argyrous (Ed.), *Evidence for policy and decision-making*. Sydney, Australia: UNSW Press.

Hastings, R. P., Remington, B., & Hatton, C. (1995). Future directions for research on staff performance in services for people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 8(4), 333-339.

Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2013). Views and values of developmental disabilities and domestic violence/sexual assault support professionals regarding the prevention and handling of situations of abuse. *Journal of Policy and Practice in Intellectual Disabilities*, 10(3), 207-214.

Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2015). Randomized controlled trial to evaluate an abuse prevention curriculum for women and men with intellectual and developmental disabilities. *American journal on intellectual and developmental disabilities*, 120(6), 490-503.

Holzer, P. J. (2007). *Defining the public health model for the child welfare services context* (Resource Sheet No. 11). Melbourne, Australia: National Child Protection Clearinghouse.

Holzer, P. J., Higgins, J., Bromfield, L. M., Richardson, N., & Higgins, D. J. (2006). The effectiveness of parent education and home visiting child maltreatment prevention programs (*Child Abuse Prevention Issues No. 24*). Melbourne, Australia: National Child Protection Clearinghouse

Hughes, K., Bellis, M., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C; Shakespeare, T., Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet*, 379(9826), 1621-1629.

Hulbert-Williams, L., & Hastings, R. P. (2008). Life events as a risk factor for psychological problems in individuals with intellectual disabilities: A critical review. *Journal of Intellectual Disability Research*, 52(11), 883-895.

Hulme, P. A., & Middleton, M. R. (2013). Psychosocial and developmental characteristics of civilly committed sex offenders. *Issues in mental health nursing*, 34(3), 141-149.

Humphreys, L., Bigby, C., Iacono, T., & Bould, E. (2016). Development of a scale to measure organisational culture in group homes. *Journal of Intellectual Disability Research*, 60, 7-8, p.685

Hutchison, A., & Stenfert Kroese, B. (2015). A review of literature exploring the possible causes of abuse and neglect in adult residential care. *The Journal of Adult Protection*, 17(4), 216-233.

Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110(3), 193-204.

Knudsen E. I., Heckman J. J., Cameron J. L., & Shonkoff J. P. (2006). Economic, neurobiological, and behavioral perspectives on building America's future workforce. *Proceedings of the National Academy of Sciences of the United States of America*, 103, 10155-10162. doi: 10.1073/pnas.0600888103

Krug, E. G., Dahlberg, L. L., Mercy, J. A., Zwi, A. B., & Lozano, R. (2015). *World Report on Violence and Health*. Geneva, Switzerland: World Health Organisation,

Krug, E. G., Mercy, J. A., Dahlberg, L. L., & Zwi, A. B. (2002). The world report on violence and health. *The Lancet*, 360 (9339), 1083-1088.

Lan-Ping, L., Chia-Feng, Y., Fang-Yu, K., Jia-Ling, W., & Jin-Ding, L. (2009). Sexual assault of people with disabilities: Results of a 2002-2007 national report in Taiwan. *Research in Developmental Disabilities*, 30, 969-975.

Levy, H., & Packman, W. (2004). Sexual abuse prevention for individuals with mental retardation: Considerations for genetic counsellors. *Journal of Genetic Counselling*, 13(3), 189-205.

Lund, E. M., & Hammond, M. (2014). Single-session intervention for abuse awareness among people with developmental disabilities. *Sexuality and Disability*, 32(1), 99-105.

Mandeville, H., & Hanson, M. (2000). Understanding caregiver abuse as domestic violence: Systemic change in Wisconsin. *Impact*, 13(3), 14-15.

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. Warriewood, Australia: Jessica Kingsley Publishers.

Mansell, J., McGill, P. & Emerson, E. (1994). Conceptualizing service provision. In E. Emerson, P. McGill & J. Mansell (Eds.), *Severe Learning Disabilities and Challenging Behaviour* (pp. 69-93). London, UK: Chapman & Hall.

Marsland, D., Oakes, P., & White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings. *The Journal of Adult Protection*, 9(4), 6-20.

Mazzucchelli, T. G. (2001). Feel safe: A pilot study of a protective behaviours programme for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 26(2), 115-126.

McCarthy, M. (1998). Sexual violence against women with learning disabilities. *Feminism & Psychology*, 8(4), 544-551.

McCartney, J. R., & Campbell, V. A. (1998). Confirmed abuse cases in public residential facilities for persons with mental retardation: A multi-state study. *Mental Retardation*, 36(6), 465-473.

McKinstry, C., Brown, T., & Gustafsson, L. (2014). Scoping reviews in occupational therapy: The what, why, and how to. *Australian occupational therapy journal*, 61(2), 58-66.

McCormack, B., Kavanagh, D., Caffrey, S., & Power, A. (2005). Investigating Sexual Abuse: Findings of a 15-Year Longitudinal Study. *Journal of Applied Research in Intellectual Disabilities*, 18(3), 217-227.

McEwan, J., Bigby, C., & Douglas, J. (2014). What are Victorian Disability Standards really measuring. *Research and Practice in Intellectual and Developmental Disability*, 2, 283-295. Doi: 10.1080/23297018.2014.956385

Meloy, J. R. (2002a). Stalking and violence. *Stalking and psychosexual obsession*, 105-124.

Meloy, J. R. (2002b). The "polymorphously perverse" psychopath: Understanding a strong empirical relationship. *Bulletin of the Menninger Clinic*, 66(3), 273-289. doi: 101521bumc66327323368

Mercy J. A., & Saul J. (2009). Creating a healthier future through early interventions for children. *Journal of the American Medical Association*, 301, 2262-2264

Mikton, C., & Shakespeare, T. (2014). Introduction to special issue on violence against people with disability. *Journal of interpersonal violence*, 29(17), 3055-3062.

Mikton, C., Maguire, H., Shakespeare, T., (2014). A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities. *Journal of Interpersonal Violence*, 29(17), 3207-3226. Doi: 10.1177/0886260514534530

Moore, D. (2001). Friend or foe?: A selective review of literature concerning abuse of adults with learning disability by those employed to care for them. *Journal of Intellectual Disabilities*, 5, 245-258.

Mouilso, E. L. & Calhoun, K.S (2016). Personality and perpetration: Narcissism among college

sexual assault perpetrators. *Violence against Women*, 22(10), 1228-1242.

Murphy G. (2007) Intellectual disabilities, sexual abuse and sexual offending. In: *Handbook of Intellectual Disability and Clinical Psychology Practice* (eds A.Carr, G.O'Reilly, P.Noonan Walsh & J.McEvoy), pp. 831–66. London, UK: Routledge.

Murphy, G., O'Callaghan, A., & Clare, I. (2007). The impact of alleged abuse on behaviour in adults with severe intellectual disabilities. *Journal of Intellectual Disability Research.*, 51(10), 741-749. doi: 10.1111/j.1365

National Disability Administrators. (2002). *Abuse prevention strategies in specialist disability services*. Retrieved from <http://www.stvp.org.au/documents/Compendium/Tools,%20Guidelines%20and%20Internal%20Policy%20Development/Abuse%20Prevention%20Strategies%20in%20Specialist%20Disability%20Services%20AUS%202002.pdf>

National Disability Services (2016). *Zero Tolerance framework*. Retrieved from <https://www.nds.org.au/resources/zero-tolerance>

Northway, R., Davies, R., Mansell, I., & Jenkins, R. (2007). “Policies don’t protect people, it’s how they are implemented”: Policy and practice in protecting people with learning disabilities from abuse. *Social Policy & Administration*, 41, 86-104.

Nosek, M. A., Howland C., Rintala D. H., Young M. E., & Chanpong G. F. (2001). National study of women with physical disabilities: Final report. *Sexuality & Disability*, 19, 5.

Nosek, M. A., Hughes R. B., Taylor H. B., & Taylor P. (2006). Disability, psychosocial, and demographic characteristics of abused women with physical disabilities. *Violence Against Women*, 12, 838–850.

Ortoleva, S., & Lewis, H. (2012). Forgotten sisters—A report on violence against women with disabilities: An overview of its nature, scope, causes and consequences, (*Northeastern University School of Law Northeastern Public Law and Theory Faculty Research Papers Series No. 104-2012*). Retrieved from <http://ssrn.com/abstract=2133332>

Ottmann, G., McVilly, K., & Maragoudaki, M. (2016). ‘I walk from trouble’: exploring safeguards with adults with intellectual disabilities—an Australian qualitative study. *Disability & Society*, 31(1), 47-63.

Senate Community Affairs Committee Secretariat. (2015). *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*. Canberra, Australia: Commonwealth of Australia.

Parliament of Victoria. (2015). *Interim Report on the Inquiry into Abuse in Disability Services*. Retrieved from https://www.parliament.vic.gov.au/file_uploads/FCDC_-_Inquiry_into_abuse_in_disability_services_HtW37zgf.pdf

Peckham, N. G., Howlett, S., & Corbett, A. (2007). Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused. *Journal of Applied Research in Intellectual Disabilities*, 20(4), 308-322.

Peckham, N. G. (2007). The vulnerability and sexual abuse of people with learning disabilities. *British Journal of Learning Disabilities*, 35(2), 131-137.

Perry, J. (2004). Hate crime against people with learning difficulties: The role of the Crime and Disorder Act and No Secrets in identification and prevention. *Journal of Adult Protection*, 6, 27-34.

Powers L. E., Renker P., Robinson-Whelen S., Oswald M., Hughes R., Swank P., & Curry M. A. (2009). Interpersonal violence and women with disabilities: Analysis of safety promoting behaviors. *Violence Against Women*, 15, 1040–1069.

Quarmby, K. (2011). *Scapegoat*. London, UK: Portobello Books.

Rees, P. & Manthorpe, J. (2010). Managers and staff experiences of adult protection allegations in mental health and learning disability residential services: a qualitative study, *British Journal of Social Work*, 40(2), 513-529.

Robinson, S. (2015). Preventing Abuse of Children and Young People with Disability under the National Disability Insurance Scheme: A Brave New World? *Australian Social Work*, 68(4), 469-482.

Robinson, S. (2013). *Preventing the emotional abuse and neglect of people with intellectual disability: Stopping insult and injury*. Warriewood, Australia: Jessica Kingsley Publishers.

Robinson, S. (2012). *Enabling and Protecting: Proactive approaches to addressing the abuse and neglect of children and young people with disability*. Retrieved from <http://a4.org.au/sites/default/files/CDA%20Enabling%20and%20Protecting%20Issues%20nPaper.pdf>

Robinson, S., & Chenoweth, L. (2012). Understanding emotional and psychological harm of people with intellectual disability: an evolving framework. *The Journal of Adult Protection*, 14(3), 110-121.

Robinson, S., & Chenoweth, L. (2011). Preventing abuse in accommodation services: From procedural response to protective cultures. *Journal of Intellectual Disabilities*, 15(1), 63-74.

Robinson, S. & Chenoweth, L. (2005) 'Off the Radar: Abuse and Neglect of People with Disability', paper delivered at *ASSID 40th Annual Conference: Out of the Ordinary? Creativity, Cooperation, Collaboration*. Auckland, New Zealand.

- Rowell, A. C., Clare, I. C., & Murphy, G. H. (2013). The psychological impact of abuse on men and women with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26(4), 257-270.
- Rusch, R. G., Hall, J. C., & Griffin, H. C. (1986). Abuse-provoking characteristics of institutionalized mentally retarded individuals. *American Journal of Mental Deficiency*, 90(6), 618-624.
- Saxton, M., Curry, M. A., Powers, L. E., Maley, S., Eckels, K., & Gross, J. (2001). "Bring my scooter so I can leave you": A study of disabled women handling abuse by personal assistance providers. *Violence Against Women*, 7, 393-417.
- Schalock, R. L., Verdugo, M. A., & Braddock, D. L. (2002). *Handbook on quality of life for human service practitioners*. Washington, USA: American Association on Mental Retardation.
- Sequeira, H., Howlin, P. & Hollins, S. (2003). Psychological disturbance associated with sexual abuse in people with learning disabilities. *British Journal of Psychiatry* 183, 451-456.
- Shonkoff, J. P., Boyce, W. T., & McEwen, B. S. (2009). Neuroscience, molecular biology, and the childhood roots of health disparities building a new framework for health promotion and disease prevention. *Journal of the American Medical Association*, 301, 2252-2259.
- Shonkoff, J. P., & Garner, A. S. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics*, 129, E232-E246. doi:10.1542/peds.2011-2663.
- Smith, D. L. (2008). Disability, gender and intimate partner violence: Relationships from the behavioral risk factor surveillance system. *Sexuality and Disability*, 26(1), 15-28
- Sobsey, D. (1994). *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* Baltimore, USA: Brookes.
- Sobsey, D., & Doe, T. (1991). Patterns of sexual abuse and assault. *Sexuality and Disability*, 9(3), 243-259.
- Stagner, M. W., & Lansing, J. (2009). Progress toward a prevention perspective. *The Future of Children*, 19(2), 19-38.
- Strand, M., Benzein, E., & Saveman, B. I. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13(4), 506-514.
- Sundram, C. J. (1985). Strategies to prevent patient abuse in public institutions. *New England journal of human services*, 6(2), 20-25.

Swedlund N. P., & Nosek M. A. (2000). An exploratory study on the work of independent living centers to address abuse of women with disabilities. *Journal of Rehabilitation*, 66, 57–64.

Teaster, P. B., Ramsey-Klawnsnik, H., Mendiondo, M. S., Abner, E., Cecil, K., & Tooms, M. (2007). From behind the shadows: A profile of the sexual abuse of older men residing in nursing homes. *Journal of Elder Abuse & Neglect*, 19(1-2), 29-45.

Terry, M. S. (2014). Applying the social ecological model to violence against women with disabilities. *Journal of Womens Health Care*, 2167-0420.

Thomas K. A., Joshi M., Wittenberg E., & McCloskey L. A. (2008). Intersections of harm and health: A qualitative study of intimate partner violence in women's lives. *Violence Against Women*, 14, 1252–1273

Ticoll, M. (1994). *Violence and People with Disabilities: A Review of the Literature*. Ontario, Canada: Roehner Institute.

Tomison, A. M. (2000). *Exploring family violence: Links between child maltreatment and domestic violence*. Melbourne, Australia: Australian Institute of Family Studies.

Turk, V., & Brown, H. (1993). The sexual abuse of adults with learning disabilities: Results of a two year incidence survey. *Journal of Applied Research in Intellectual Disabilities*, 6(3), 193-216.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from <http://www.refworld.org/docid/45f973632.html>

Victorian Ombudsman. (2015). *Reporting and investigation of allegations of abuse in the disability sector: phase 1 – the effectiveness of statutory oversight*. Retrieved from <https://www.ombudsman.vic.gov.au/getattachment/c6499f78-0eec-4e4a-8e94-e4cd716a64f8>

Wang, J. J. (2005). Psychological abuse behaviour exhibited by caregivers in the care of the elderly and correlated factors in long-term care facilities in Taiwan. *Journal of Nursing Research*, 13(4), 271-280.

White, C., Holland, E., Marsland, D. & Oakes, P. (2003) 'The Identification of Environments and Cultures That Promote the Abuse of People with Intellectual Disabilities: A Review of the Literature'. *Journal of Applied Research in Intellectual Disabilities*, 19: 1-9.

Wigham, S., Hatton, C., & Taylor, J. L. (2011). The effects of traumatizing life events on people with intellectual disabilities: A systematic review. *Journal of Mental Health Research in Intellectual Disabilities*, 4(1), 19-39.

Women with Disabilities Australia (WWDA). (2012). An overview of its nature, scope, causes and consequences (*Northeastern University School of Law Northeastern Public Law and Theory Faculty Research Papers Series No. 104-2012*).

Women with Disabilities Australia (WWDA). (2011). *Submission to the UN Analytical Study on Violence against Women and Girls with Disabilities*. Lenah Valley, Australia: WWDA.

World Health Organization (WHO). (2009). *Violence prevention: The evidence*. Geneva, Switzerland: WHO.

World Health Organization (WHO). (2011). *World report on disability*. Geneva, Switzerland: WHO.

World Health Organization (WHO). (2013). *Fact sheets*. Retrieved from <http://www.who.int/mediacentre/factsheets/en/>