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# Disability and child sexual abuse in institutional contexts



# Disability and child sexual abuse in institutional contexts

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# Preface

On Friday 11 January 2013, the Governor-General appointed a six-member Royal Commission to inquire into how institutions with a responsibility for children have managed and responded to allegations and instances of child sexual abuse.

The Royal Commission is tasked with investigating where systems have failed to protect children, and making recommendations on how to improve laws, policies and practices to prevent and better respond to child sexual abuse in institutions.

The Royal Commission has developed a comprehensive research program to support its work and to inform its findings and recommendations. The program focuses on eight themes:

1. Why does child sexual abuse occur in institutions?
2. How can child sexual abuse in institutions be prevented?
3. How can child sexual abuse be better identified?
4. How should institutions respond where child sexual abuse has occurred?
5. How should government and statutory authorities respond?
6. What are the treatment and support needs of victims/survivors and their families?
7. What is the history of particular institutions of interest?

How do we ensure the Royal Commission has a positive impact?

This research report falls within theme 1.

The research program means the Royal Commission can:

- obtain relevant background information
- fill key evidence gaps
- explore what is known and what works
- develop recommendations that are informed by evidence, can be implemented and respond to contemporary issues.

For more on this program, please visit

[www.childabuseroyalcommission.gov.au/research](http://www.childabuseroyalcommission.gov.au/research)



# Contents

Executive summary .....	1
SECTION 1 Scope of the discussion paper .....	3
1.1 Research questions .....	3
1.2 Overall approach.....	3
1.2.1 Child-centred framework .....	5
1.3 Defining disability .....	5
1.4 Children with disability, sexual abuse and institutional responses .....	6
SECTION 2 Understandings of disability in Australia .....	8
2.1 Population of children with disability .....	9
2.2 Overview of current understandings of disability.....	10
2.2.1 Official understanding of disability .....	10
2.2.2 Disability as (negative) difference.....	11
2.3 Previous understandings of disability .....	12
2.3.1 Pre-1950s internationally.....	12
2.3.2 Pre-1950s in Australia.....	14
2.3.3 1960s and 1970s.....	16
2.3.4 1980s and 1990s.....	17
2.4 2000s onwards.....	24
2.4.1 The national disability reform agenda.....	24
2.4.2 Exclusion of children with disability .....	25
2.4.3 Disability as a risk factor in care and protection frameworks .....	26
2.5 Shape of the current disability service system and policies and practices .	27
2.5.1 Quality and safeguards .....	28
2.5.2 Assumptions which underpin responses to sexual abuse of children with disability .....	31
SECTION 3 Interactions that influence the risk of sexual abuse of children with disability in institutional contexts.....	33
3.1 Overview .....	33
3.1.1 Multiple, interacting factors.....	34
3.1.2 Overlooked factors .....	35
3.2 Conceptual framework .....	35
3.2.1 Difficulties in relying on international data .....	36
3.3 Search methods.....	37
3.3.1 Scientific literature.....	37
3.3.2 Grey literature .....	38
3.4 Description of literature .....	38
3.5 Findings .....	42
3.5.1 Prevalence .....	42
3.5.2 Risk.....	44
3.5.3 Heterogeneity.....	45
3.5.4 Child characteristics .....	46
3.5.5 Family factors.....	48
3.5.6 Environmental context.....	48
3.6 How risk is understood in the grey literature.....	49

SECTION 4	Key factors in the prevention of sexual abuse of children with disability in institutional contexts in the future .....	52
4.1	Overview .....	52
4.2	Conceptual framework .....	52
4.3	Search methods .....	53
4.3.1	Scientific literature .....	53
4.3.2	Grey literature .....	54
4.4	Understanding prevention strategies and evaluation .....	54
4.4.1	Evaluation studies .....	54
4.5	Prevention of sexual abuse of children with disability .....	56
4.5.1	Prevention strategies/interventions focused on the child .....	57
4.5.2	Family prevention strategies .....	59
4.5.3	Prevention strategies for staff/managers of organisations .....	60
4.5.4	Prevention strategies with an organisation / community focus.....	62
4.6	Two contributions from the international grey literature .....	63
SECTION 5	Synopsis and key messages .....	65
5.1	Disability reform in Australia .....	65
5.1.1	Exclusion and mental treatment .....	65
5.1.2	First wave of reform – recognising the rights of people with disability	65
5.1.3	Second wave of reform – towards realising the rights of people with disability .....	66
5.2	Children with disability and their vulnerability to harm .....	67
5.2.1	Prevalence and risk of sexual abuse for children with disability .....	67
5.2.2	Prevention approaches .....	68
5.3	New directions for children with disability .....	70
Appendix	.....	72
References	.....	79

# List of abbreviations

ABS	Australian Bureau of Statistics
ADD	Attention deficit disorder
ADHD	Attention deficit hyperactivity disorder
AIHW	Australian Institute of Health and Welfare
ALRC	Australian Law Reform Council
CI	Confidence interval
COAG	Council of Australian Governments
CROC	UN Convention on the Rights of the Child
CRPD	UN Convention on the Rights of Persons with Disability
CRS	Commonwealth Rehabilitation Service
CSC	Community Services Commission
CSDAs	Commonwealth-State Disability Agreements
CYDA	Children and Young People with Disability Australia
DDA	Disability Discrimination Act
DPO	Disabled People's Organisations
ICF	International Classification of Functioning, Disability and Health
IYDP	International Year of Disabled Persons
NDIS	National Disability Insurance Scheme
NDRDA	National Disability Research and Development Agenda
NDS	National Disability Strategy 2010–2020
PWDA	People with Disability Australia
RQ	Research question
SDAC	Survey of Disability, Ageing and Carers
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

# Executive summary

Children and young people with disability are often absent in discussions about child sexual abuse as people with disability are left out of discussions about violence, abuse and neglect. This is due in part to individuals with disability being excluded from society, hidden away in institutions or in family homes. Community attitudes contribute to and are informed by the fact that people with disability, including children, are often seen in segregated, special and demeaning settings. This situation is changing slowly. People with disability are taking their rightful place as citizens actively contributing to and increasingly benefiting from all that our society has to offer.

Segregation and exclusion in closed institutional contexts away from public scrutiny leaves children (and adults) with disability at heightened risk of violence and harm including sexual abuse. Further, when children with disability are stereotyped as dependent and passive and unable to 'speak up', they are at heightened vulnerability to being segregated, abused, overlooked and not heard. The Royal Commission into Institutional Responses to Child Sexual Abuse recognised early on the likely particular vulnerabilities of children with disability and the institutional contexts which they encounter. This commissioned discussion paper set out to provide a reasoned analysis of the historical, social and policy context surrounding children with disability and to examine the evidence about prevalence and prevention of sexual abuse of children with disability in institutional contexts.

To achieve this aim we proceeded iteratively and conceptually, drawing on our expertise and cumulative experience of over 60 years in disability, child and family studies, and care and protection. We used reports, submissions, position papers and scientific literature in Australia to analyse past approaches to children with disability and the present context of the changing nature of disability services in Australia. While the paper draws from materials that are relevant to Australia as a whole, some documents from New South Wales are used to illustrate specific points. Just as children and young people with disability are rarely present in discussions about sexual abuse, they are also remarkably absent from Australian literature on this subject. This is a major failing: we do not know the extent of sexual abuse of Australian children with disability.

We therefore turned to international literature to identify prevalence figures and to examine the interactions between impairment and environment and their potential influence on the risk of sexual abuse. We found that internationally there is no clearly developed evidence base for the prevalence and risk of sexual abuse of children with disability. We provide an analysis and critique of international prevalence and risk figures and the application of these in the Australian context.

Quality of care and safeguarding processes form the basis of the disability reform agenda in Australia and also of the incoming market approach to specialist support and service delivery, which relies on mainstreaming, and building inclusive and accessible communities. This has led to debate on possible fail-safe governance



mechanisms and prevention strategies, although with remarkably less focus on children and young people with disability.

There is an absence of empirical data in Australia on strategies to prevent sexual abuse of children with disability in institutional contexts. Again, we turned to the international literature to source information on relevant key factors. We approached this from a public health perspective that recognises the need to implement both population-based and targeted interventions.

In this discussion paper we argue the need to put aside the community perception that disability is embedded within the child. This is not the official understanding of disability in Australia. Instead, disability is understood as arising from interactions between individuals with impairment and the various barriers that may hinder (their) full and effective participation in society on an equal basis with others. This understanding comes from the International Classification of Functioning, Disability and Health (ICF). We adhere to the key frameworks of the United Nations (UN) Convention on the Rights of the Child (CROC) and the UN Convention on the Rights of Persons with Disabilities (CRPD). These international covenants require that children with disability are considered as children first, with disability considered as only one feature and not the *defining feature* of their everyday lives.

We also present an analysis and critique of the available literature on prevention of sexual abuse, noting the pitfalls in assuming a 'special group' approach to children with disability or a broad-brush approach to diversity. The human rights perspective is embedded within Australian legislation and policy directives in disability. It provides an excellent foundation to ensure that children with disability and their rights are more visible and to give them the same priority as other children. This is essential to ensure children with disability are safe in institutional contexts in the future.

# SECTION 1 Scope of the discussion paper

In February 2016, the Royal Commission commissioned a succinct discussion paper on disability and child sexual abuse in institutional contexts. The discussion paper aimed to explore (i) the relationship between understandings of disability and the disability service system in Australia over time and currently, (ii) the interaction between characteristics of a child's impairment and the environment which may lead to the sexual abuse of children with disability in institutional contexts, and (iii) evidence-based prevention approaches to sexual abuse of children with disability with a particular focus on children with disability in institutional contexts in the future.

## 1.1 Research questions

1. How have understandings of disability in Australia changed over time and how has this influenced the shape of the current Australian disability service system (for example, structure, models of service delivery and practices/behaviours)?
2. How do characteristics of a child's impairment and their environment interact in ways that influence the risk of child sexual abuse in institutions?
3. What does the evidence point to as the key factors in the prevention of the sexual abuse of children with a disability in institutional contexts in the future?

## 1.2 Overall approach

In response to research question 1 the discussion paper describes and critically analyses the legislative, policy and governance frameworks in relation to children with disability in institutional contexts in Australia briefly with regard to prior to the 1950s and with more detail over the subsequent decades. Section 2 discusses key historical events that have shaped and continue to shape the understanding of disability in Australia. The emphasis in our analysis and discussion is purposely given to two institutional contexts: where children with disability live and the education of children with disability.

To provide a nationwide perspective, the primary focus is on historical developments across Australia. To illustrate particular points, we draw primarily on working papers, submissions and reports from New South Wales due to the ease of accessing them in the time available to complete this discussion paper. In our view, similar analysis should be undertaken for each state and territory. This task was beyond the remit of this discussion paper.

In section 2, we also present the way in which people's understanding of disability influences legislation and policy development as well as service system responses, models of service delivery, and practices and behaviours. Understandings about disability at this level are not necessarily the same as popular understandings of disability. The paper presents two concurrent and competing understandings about disability in Australia. The 'official' perspective understands individuals with disability as rights-bearers for whom government bears the responsibility to remove barriers to their full participation in society. The competing understanding locates disability as (negative) difference requiring specialist solutions from the medical/ health sector.

In response to Research Question 2, section 3 of the discussion paper critically analyses the evidence on the prevalence of sexual abuse of children with disability and the concept of risk, drawing on empirical research and grey literature where appropriate. The scope of this discussion paper did not allow for a comprehensive international search of individual studies. Accordingly, we used the most recent meta-analysis published in the *Lancet* in 2012 as the reference document and updated this meta-analysis with more recent empirical studies.

Research question 3 is addressed in section 4. This section critically analyses the evidence in relation to prevention of sexual abuse of children with disability by seeking evidence-informed and evidence generating approaches. There is a dearth of Australian (and international) evaluations of prevention strategies in relation to sexual abuse of children with disability. A comprehensive international search of individual studies was not feasible within the scope of the discussion paper. Accordingly we turned to the most recent systematic review on violence against people with disabilities published in 2014 and conducted Web of Science and Scopus citation reports for this study to identify more recently published empirical studies.

The Australian grey literature has significantly expanded with the presence of the Royal Commission and national and state-based commissions and committees of inquiry into violence and/or abuse and neglect of people with disability over the past five or so years. This is a welcome development. The major quantum comprises submissions to and reports from these inquiries, as well as commissioned papers and position statements from the disability sector. There are several limitations to this grey literature. This literature primarily cites selected international studies on prevalence and risk. There is little attention to evidence-based prevention. Most of the materials focus on adults with disability, with far less attention to children with disability. There is limited attention to the heavy presence of institutional contexts in the daily lives of children with disability.

In the absence of an evidence base in Australia, the discussion paper turns to international evidence on sexual abuse and children with disability and to the literature on sexual abuse for children more generally where necessary. This is partly pragmatic given this much larger literature (Kaufman & Erooga, 2016). It is also because we take a child-centred approach: children with disability are considered as children first. Disability is only one part of their lives; it is not necessarily the defining part.

### 1.2.1 Child-centred framework

There is potentially much to learn from using a child-centred framework to understand sexual abuse of children with disability. A child-centred framework means that children with disability are regarded as active agents in their own lives. This does not mean that any particularities of disability are ignored or neglected. Rather, as Power, Lord and DeFranco (2013) noted the question becomes how the state might reform its approach from their paramount focus on disability which led in the past (and continues to do so) to excluding people with disability from society and paternalistic approaches to their 'care' and support.

Creating safe environments is critical for children with disability. Population approaches to prevention are important to ensure safe institutional contexts for all children (Commonwealth of Australia 2009a; UNICEF GPCW, 2015). The strength of a population approach resides in providing evidence-based prevention 'interventions' to the whole population. For example, seat belts and road safety, or, as in the current case, creating safe institutional contexts.

The downside of a population approach is effectively addressing outliers. That is, reducing the risk for those individuals who are more likely to be significantly exposed to unsafe institutional contexts. These individuals and their institutional contexts require targeted interventions (Ballard & Syme, 2016; Krahn & Campbell, 2011). This is not the case currently for children with disability in Australia.

The Australian national framework for protecting children takes a population approach. Disability is mentioned only briefly in relation to parental risk factors under Supporting Outcome 3 'childhood disability, mental health and/or behavioural problems' (Commonwealth of Australia, 2009a, p 21). Risk is located in the child. This leads to actions to support families rather than children. Only one of the five actions (the last dot point on p 22) mentions safeguards for children.

When risk is assumed to be the child's problem, we are of the view that the place of institutional contexts in child sexual abuse is downplayed or ignored. Locating risk in disability *per se* provides little guidance on targeted interventions to ensure all children with disability are safe in the range of institutional contexts to which they are exposed.

This discussion paper aims to explore the question of which children with disability are at risk of sexual abuse, under what circumstances, and to what extent. Answers to this question will assist in developing *effective population approaches and targeted interventions* to prevent the sexual abuse of Australian children with disability.

## 1.3 Defining disability

Critical to a reading of this discussion paper is how disability is defined in Australia. We use the definition of disability in Australian statistical collections and recent legislation. This definition comes from the *International classification of functioning, disability and health* (ICF) (WHO, 2002). The ICF definition informed the description

of disability in the *UN convention on the rights of persons with disabilities* (CRPD) (UN, 2006).

The Australian Bureau of Statistics (ABS) is responsible for the definition of disability in Australia. The baseline survey is the *Survey of disability, ageing and carers* (SDAC) carried out approximately every three to five years since 1988. Individuals with disability are defined as: any person with a limitation, restriction or impairment which has lasted or is likely to last, for at least six months and restricts everyday activities. Self-care, mobility and communication are defined as core activities. Core activity restriction can be mild, moderate, severe or profound.

In common parlance disability is generally thought to 'belong to' an individual as an inherent characteristic of that person. The CRPD is at pains to point out that this is not the case. Rather disability is described as: 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments *which in interaction with various barriers* may hinder their full and effective participation in society on an equal basis with others' (Article 1). This description is drawn from the bio-psycho-social model of disability, which also informs the ICF. The bio-psycho-social model explains that human functioning is the outcome of interactions between the biological and the psycho-social components of life. *Ipsa facto*, when difficulties in human functioning occur these result from bio-psycho-social interactions. When these difficulties are long term (typically operationalised as six months or more), this is disability. Disability, however, is not an inevitable outcome of functioning difficulties. Disability results from difficulties in functioning *in interaction* with environmental and personal factors. It is quite possible to have an impairment, health condition or chronic illness and not to be disabled depending on personal and environmental factors.

## 1.4 Children with disability, sexual abuse and institutional responses

The focus of this discussion paper aligns directly with the Royal Commission's definitions of child sexual abuse and institutional contexts.

Does the Royal Commission's definition of sexual abuse apply to children with disability in ways that may be different from non-disabled children? Children with impairments, health conditions and chronic illnesses are 'handled' more often and by a greater range of adults than their non-disabled peers. Although this is not essentially problematic, there is evidence to suggest that children with disability whose bodies are frequently touched by non-family carers may find it more difficult to differentiate, or object to, the invasion of private parts of their bodies (Robinson, 2012). Children with high physical support needs (those unable to care for their daily personal hygiene and bodily functions) will have adults carrying out these daily tasks. This creates the potential for abuse under the guise of assistance for physical support needs.

With regard to the Royal Commission's definition of institution, children with disability spend a great deal of time in a range of institutional contexts. Some of these settings are the same as those for their non-disabled peers; for example, regular classes in school. Some however are quite different; such as, special units or special schools. There are also service settings which are disability specific and not available to children without disability. Respite care (disability) is one such service setting.

Children with disability may also spend longer time periods in institutional contexts than their non-disabled peers. For children with disability with a health condition or chronic illness there is often extended contact with the health sector in hospital and/or with one or more health service providers. The school leaving age for young people with disability may be extend several years older than their non-disabled peers. This is to give young people with intellectual or multiple impairments extended opportunities to learn.

Policy settings designed to relieve the caring responsibilities of parents and families actively encourage children with disability to spend more time in institutional contexts. Respite care is one example. A range of models of relief extend the likelihood that more families of children with disability will take advantage of this relief. In New South Wales for example, the *Respite care guidelines (disability)* (FACS/ADHC April, 2010 Revised January, 2011) lists nine types of respite care: own home, family, peer support, flexible, teen time, afterschool and vacation support, respite camps, family solutions program, and centre-based (p i). Another example comes from the incentive for pre-schools to enrol children with disability and for longer hours of attendance. This policy mechanism is predicated on giving children with disability or developmental delay more intensive programming and opportunities for socialisation than are normally available in the family home. School transport for children with disability is another policy mechanism which places children with disability in contexts where they are alone with one unknown adult at an age younger than most other children.

In summary, it is the authors' view that a child-centred framework is needed to understand children with disability as children first living everyday lives as children in our society. Their everyday lives however may differ substantially from their non-disabled peers with regard to the institutional activities and contexts in which they spend extended time periods. Exclusionary practices based on stereotyping children with disability as less capable, more dependent and less sexual than their peers may also lead to 'over protection' and greater vulnerability.



## SECTION 2 Understandings of disability in Australia

- Australia collects data on disability in the Survey of Disability, Ageing and Carers (SDAC) conducted approximately every five years. Latest data on the proportion of children with disability (0-14 years) in the general population is 6.1 per cent (ABS 2012).
- In Australia, residential institutional care for people with disability over the nineteenth and twentieth century followed similar patterns to those in the United Kingdom, Europe and North America. People with disability were seen through a medical lens and children and adults, particularly those with cognitive disability, were 'put away' in government and privately owned institutions.
- During the 1960s and 1970s, the state became increasingly co-involved with families in providing care for children with disability. A significant milestone was the introduction of the Handicapped Child's Allowance in 1974 to assist families to care for their children at home.
- From the 1970s the principle of normalisation began to influence thinking in Australia. A series of reports identified significant shortcomings in disability programs and profound detrimental effects for people with disability segregated from the wider community.
- Changes in Australian Government thinking about disability were also driven by the International Year of Disabled Persons (IYDP) in 1981. The *New directions report* (1983) for the first time identified people with disability as people first, disabled second, a watershed in Australian Government thinking about disability. The Disability Services Act 1986 (Commonwealth of Australia), based in a human rights framework, recognised that people with disability have the same rights as do other members of society.
- By the early 2000s, the Australian Government looked to the National People with Disability and Carers Council to provide expert advice and information on the development and implementation of a national disability strategy.
- The National Disability Strategy 2010–2020 (2011) brought to the fore the human rights of people with disability and specifically promoted their social and economic participation in Australian society.
- Disability as a risk factor in maltreatment and abuse was helpful in the past in drawing welcome attention to maltreatment of children with disability in institutional contexts. The downside is that disability as risk approach is not in line with Australia's international obligations or national legislation to consider children with disability as children first, disabled second. It also hinders much needed robust data collection and empirical evidence to understand which children with disability are more likely to be at heightened risk of sexual abuse and in what contexts.

## 2.1 Population of children with disability

Since 1988, Australian data on children with disability has been available from the SDAC. This national survey on people with disability is useful to understand within group characteristics of people with disability in Australia. It is not designed to address differences between people with disabilities and their non-disabled peers. The data on Australian children with disability is reported in occasional bulletins from the Australian Bureau of Statistics (ABS), and annually by the Australian Institute of Health and Welfare (AIHW) in Australia's welfare publications (available at <http://www.aihw.gov.au/australias-welfare-publications/>). The data from SDAC covers children aged 0-14 years. Features of SDAC have changed over time; the relevant data for our current purpose comes from 2003, 2009, 2012 and 2015. However, the 2015 SDAC data on children with disability is yet to be released.

Drawing on 2003 SDAC, the AIHW (2006) reported 8.3 per cent (1 in 12) of Australians with disability were children (317,000). About half of these children – 165,300 – had a severe or profound disability. Of all children with disability, those with autism and intellectual impairment were more likely to have a severe or profound activity limitation. Boys were more likely than girls to have a disability (10 per cent compared to 6.5 per cent); almost all children (97 per cent) aged 5-14 years with a disability were attending school; 89 per cent in mainstream schools and 9 per cent in special schools. Disability prevalence rates were higher in the 5-14 year age range, particularly for intellectual/learning disability. This is explained by a child's intellectual/learning disability being identified at school, where this impairment becomes most obvious, or disabling (Emerson & Grover, 2012).

In June 2012, the ABS produced *Australian Social Trends June 2012: Children with a disability* based on data from the ABS in the 2003 and 2009 SDAC. For the first time, the ABS reported the proportion of children with disability (0-14 years) in the general population averaging at 6.1 per cent (3.4 per cent in 0-4 age range and 8.8 per cent in 5-14 age range, ABS, 2012). Of the four million Australians in 2009 who had a disability, 290,000 (7.2 per cent) were children aged 0-14 years. Again, boys aged 0-14 years were more likely to have a disability (8.8 per cent) than girls (5.0 per cent). Disability rates increased with age from 3.4 per cent of children aged 0-4 years to 8.8 per cent of children aged 5-14 years. In the 5-14 year age range, boys were nearly twice as likely (11.4 per cent) to have a disability than girls (6.1 per cent). The differences in intellectual disability in the school years are clearly seen in the 2009 data. Almost two thirds (61 per cent) of children with a disability aged 5-14 years had intellectual disability, more than twice the proportion of children aged 0-4 years with an intellectual disability (29 per cent). Nearly all (98 per cent) school-aged children (5-14 years) with a disability attended school.

Relevant findings from the 2012 SDAC reported in *Australia's Welfare 2015* (AIHW 2015) demonstrate that more boys than girls in the age group 5 to 14 years continue to have a disability (11.2 per cent compared with 6.2 per cent); and, that the prevalence of severe and profound disability continues to be much higher among boys aged 5-14 years compared with girls of the same age (6.3 per cent and 3.2 per cent respectively).

The key points are that more boys than girls have a disability, the proportion of children with intellectual disability typically doubles at school age, almost all Australian children with a disability aged five to fourteen attend school, and children with disability comprise on average around 6 per cent of the total Australian population.

## 2.2 Overview of current understandings of disability

### 2.2.1 Official understanding of disability

The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted on 13 December 2006 at the 68th session of the United Nations General Assembly and opened for signature with the Optional Protocol on 20 March 2007. (Australia signed the CRPD on 17 July 2007 and ratified the convention and the optional protocol on 21 August 2008). The purpose of CRPD is: 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (Article 1). CRPD draws its definition of disability from the International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Assembly in May 2001.

In the international standard language of the ICF, functioning and disability are understood as umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and societal perspective. Thus, the ICF brought together the two major models of disability at this time – the medical and the social – as a bio-psycho-social synthesis. This bio-psycho-social model of disability recognises the role of environmental factors in the creation of disability in interaction with impairment, long-term illness or a chronic health condition.

Australia was an early adopter of the international standard classification of disability. The first international classification, ICF, was published in 1980 by the World Health Organisation (WHO). (This was progressively revised to become the ICF released in 2002). The first survey of disability in Australia was conducted by the ABS during the IYDP, 1981, based on the earlier classification.

For the last 10 to 15 years in Australia, the official perspective on disability found in legislation, government policy and planning frameworks, and population statistics comes from the concepts of person-environment interaction (from the ICF), functioning and disability (from the ICF) and human rights (from the CRPD). The official understanding of disability in Australia also borrows from the social model of disability. In the more extreme forms, disability is thought to be entirely caused by society. This means that society disables individuals by negative attitudes and stigma which in turn create barriers to, and exclusion of, people with disabilities from social and economic participation. There is no single social model. Social model theorists

place differing emphasis on the extent to which societal barriers cause disability (Shakespeare, 2014). Critically important to all versions of the social model however is the understanding that disability is not an inherent characteristic of a person; rather, disability is the result of barriers and facilitators in the social-cultural environment.

The rights/social responsibility framework underpins, for example, the National Disability Strategy, 2014–2020 (Commonwealth of Australia, 2011a) which also contains another concept – the economic imperative ‘to encourage workforce participation and build human capital’ (page 19). The National Disability Strategy 2010–2020 informs the National Disability Reform Agenda along with the National Disability Agreement (COAG 2009), the National Carer Strategy (Commonwealth of Australia, 2011c), National Disability Research and Development Agenda (Department of Social Services, 2011), the Productivity Commission Inquiry into National Disability Long-term Care and Support Scheme (Commonwealth of Australia 2011b) and, subsequently, the National Disability Insurance Scheme (Commonwealth of Australia, 2013). Full implementation of the national disability reform agenda would result in individuals with disability being considered first as equal citizens, with their ‘disability’ being considered second. Some progress has been made towards realising this person-centred, active citizenship approach.

### **2.2.2 Disability as (negative) difference**

The competing, longer term understanding is one that locates disability within the individual – as an inherent characteristic of their being. This understanding aligns with the public/private divide in which families are thought to be responsible for what happens ‘inside’ the family (the private arena) and the state is responsible for that which is ‘outside’ the family (Fraser, 1998; Young, 1998). The impact of this understanding is seen across the globe where people with disability rely primarily on family or charity. When impairments in childhood are understood as medical conditions – for example, cerebral palsy, epilepsy, Fragile X, Down syndrome – medical solutions are sought. When the impairment, health condition or chronic illness is prioritised over the everyday life of the person, the disability is treated as a technical problem with responsibility for persons with disability then being given to those with technical expertise. This is the medical model of disability (WHO, 2011).

In our view this medical understanding continues to permeate professional, community and popular (media) understandings of disability. Prior to the last decade, this was also how disability was defined in legislation and policy frameworks. Note, for example, the definition of disability in the Disability Discrimination Act 1992 (Commonwealth of Australia) by 10 separate points on loss, disorder and malfunction, the last stating that ‘disability is imputed to a person’. Scholars argue that disabled individuals, because their impairment is regarded as loss, are considered ‘less than’ others, lacking capacity and therefore needing (charitable) support (for example, Fraser & Llewellyn, 2015; Meekosha, 2006). This understanding can also encompass people with disability as heroes overcoming their afflictions and the tragedies of their lives (for example, Wedgwood, 2014).

To understand why two quite different understandings of disability coexist in Australia, we turn now to previous understandings of disability internationally and in Australia. This is presented chronologically from pre-1950s and over the decades of the 1960s to 1970s, 1970s to 1980s, 1980s to 1990s and post 2000. In each decade, drivers of change and their impact are discussed followed by consideration of changes for children with disability in living arrangements and education.

## 2.3 Previous understandings of disability

### 2.3.1 Pre-1950s internationally

Disability (more accurately, impairment) has rarely been accepted as a natural human phenomenon. Rather people with disability, throughout the ages and across countries and cultures have been discarded, disrespected and treated as outcasts. What informs this apparently universal negative disposition towards people with disability? In many cultures, disability may be seen as retribution for past sins or those of one's ancestors, a sign of witchcraft or evil spirits, or a bad omen (Bickenbach 2009; Ingstad & Whyte 1995; Lewis-Gargett et al., 2015). Theorists such as Campbell (2009) proposed the concept of ableism to explain the universal negative disposition towards disability. Ableism comes from the able-bodied attracting positive value. In contrast, the disable-bodied attract negative value and become regarded as inferior and are treated accordingly.

Although people with disability have been located at the margins of society, texts of the world religions frequently offer contradictory messages about disability, suggesting charitable responses on the one hand and disability 'meted out as punishment by God' on the other (Braddock & Parish 2001, p 14). Past understandings of disability also vary dependent on onset of disability, historical and societal timing and social class and can be contradictory. So, for example, while infanticide was not unusual when impairment was easily recognisable at birth, adult males disabled as a consequence of war are usually lauded as heroes. There are echoes of this currently in the notable absence of congratulations at the birth of a child with impairment in contrast to the attention paid to paralympics sporting figures (Goggin & Newell 2000).

'Disfigurement' has also been accepted in those of royal or high social status. While present understandings of confining people with disability to institutions are invariably negative, the historical record suggests otherwise. As Braddock and Parish (2001) note there is evidence that during the middle ages institutional care was by and large benevolent when, for example, mental disability was thought to be divinely inspired rather than of 'demonic' origin.

With the rise of the scientific method and the beginnings of modern medicine, new understandings of disability came about. These offered the possibility of cure for at least some human ailments. In this curative period, efforts were directed to minimising the impact of being blind, deaf or being 'lame'. With the Age of

Enlightenment came the possibility of new psychological and educational interventions particularly for mental illness and intellectual disability. At the same time, societal initiatives and 'moral treatment' were introduced to overcome the vicissitudes of poverty and inability to work associated with disability. (Inability to work remains a major determinant in Australian and international social policy responses to disability.)

The change from institutions being places of treatment to places of removal from society's gaze came around the turn of the 20th century. This change was in response to fewer 'curative' successes than anticipated. This resulted in public apathy, the decline of moral treatment, and overcrowding in institutions. Eugenic ideas spread at this time to change thinking and the appropriate treatment of 'deviance', particularly intellectual disability and mental illness.

The eugenics movement led to the involuntary sterilisation of many women (and some men) with intellectual disability to protect society against what were considered the ravages of moral degeneration and unacceptable social costs of procreation. In that time of belief in the inheritability of intellectual (in)capacity, it is not so surprising to encounter the now famous words of Justice Wendell Holmes of the Supreme Court of the United States writing in relation to the sterilisation of a woman with intellectual disability that 'three generations of imbeciles is enough' (Supreme Court of the United States, 1927, *Buck v. Bell*).

Understandings of impairments such as blindness and deafness developed along different pathways. Access to schooling illustrates the (generally) charitable approaches to those who could not hear or see. Residential schools were established in the early nineteenth century in the United States, for example, for children who were deaf and for those who were blind as part of the charitable movement of care and education for less fortunate children (Braddock & Parish 2001). These residential schools remain in many parts of the world today, including Australia and its neighbouring countries in the Pacific and South-East Asia. In contrast, children with intellectual disability and those with more severe and profound disability were denied access to education, and continued to live at home, or when families were no longer able to provide care, were placed in 'mental' institutions.

This situation did not change substantially until around the mid-twentieth century. For example, by the 1970s a new era had commenced in the United States (Braddock & Parish, 2001). Public schools as a child-serving agency were increasingly requested to provide services for 'severely handicapped' children. Ongoing efforts by parents, who recognised the inhumanity of warehousing children, even when their disability were severe and profound, resulted in legal action and states assuming responsibility for educating children with disability. As Schipper, Wilson and Wolf (1997) noted it was no longer seen as appropriate for society to deny education to those children who were most in need of opportunities for learning. We turn now to Australia in the pre-1950s.



### 2.3.2 Pre-1950s in Australia

As noted by Mary Lindsay in her *Background paper 2: Commonwealth disability policy 1983–1995* (Lindsay, n.d.) at the turn of the twentieth century, apart from those committed to ‘mental’ institutions, people with disability in Australia – children and adults – relied on their families for sustenance and care. ‘Mental’ institutions were considered health facilities and therefore funded by state departments of health. This remained the case after federation. Charitable relief, with some support from state governments was provided for those who were destitute or unemployed. Following the formation of the Commonwealth in 1901, the first national ‘flat-rate’ means-tested invalid pension was introduced in 1908 for those unable to work, and is considered to be the first direct involvement of the Australian Government with people with disability.

Lindsay (n.d.) notes that the impact of deaths and injury from two world wars on women and children and the return of injured, sick and ‘permanently disabled’ soldiers led to an expansion in benefits. The Vocational Training Scheme for Invalid Pensioners was introduced in 1941 becoming by 1948, the Commonwealth Rehabilitation Service, changing to CRS Australia in 1998 and remaining so today. The primary function of the CRS Australia is to provide vocational rehabilitation and employment–related services to the Australian Government and now also to the private sector. A focus on employment has remained central to Australian Government social policy on disability, including, for example, the introduction of the sheltered employment allowance in 1967. Other employment associated benefits were introduced later, such as the mobility allowance to facilitate entry to, or remaining in, the workforce.

#### 2.3.2.1 Institutional care or family care

In Australia, residential institutional care for people with disability over the nineteenth and twentieth century followed similar patterns to those in the United Kingdom, Europe and North America (Lindsay, n.d.). By and large, residential care was for children and adults with intellectual disability and adults with mental illness all of whom lived on the same grounds, although in different wards. In Australia, prior to the 1950s, parents of children with disability (except for polio, tuberculosis, and children who were deaf or blind) had the choice of caring for them at home or committing them to a state mental hospital. For example, in 1867 the Children’s Cottages at Kew, Victoria (part of Kew Asylum) opened to provide living accommodation and education for ‘mentally retarded’ children.

Government departments of health operated public institutions across the country: in New South Wales institutions – such as Marsden Hospital Parramatta and Watt Street Hospital in Newcastle – regularly received younger and older children throughout the 1950s and into the next several decades. Grosvenor Hospital at Summer Hill was a psychiatric facility and disability institution established by the New South Wales Government in 1965. It was operated by the Health Department and occupied the buildings that had been the Benevolent Society’s Renwick Home for Infants. It provided care for children with disability until the 1980s. In 1985, it stopped

being listed as a hospital for the developmentally disabled and became known as the Grosvenor Centre.

There were also charitable and privately owned institutions for children with disability. The Lorna Hodgkinson Sunshine Home at Gore Hill was founded in 1924 to educate people with intellectual disability. 'Sunshine' continued as a residential facility taking in young children, adolescents and adults with intellectual disability (many with accompanying physical and/or sensory impairments) up to the early 1990s. Allowah Babies Hospital which was established in 1954 initially took in severely handicapped children under two years of age. Later, expanding on its Dundas site, where it continues today, as the Allowah Presbyterian Children's Hospital, to provide care for children and young people with disability up to 18 years.

Many of the government and non-government institutions housing children with disability have been investigated (or named) in inquiries since the early nineteenth century to the present. This is well documented in Swain's (2014) report to the Royal Commission titled *History of Australian inquiries reviewing institutions providing care for children*.

As well as the disability specific institutions, residential settings for children also included children with disability. Concern about institutional care of children in Australia came to a head in 2003 when the Australian Senate referred an inquiry to the Senate Community Affairs References Committee to inquire into institutional care. There is frequent mention of disability in both reports of this Senate inquiry. The second report, *Protecting vulnerable children* (Commonwealth of Australia, 2005), points out that large-scale, institutional accommodation of children with disabilities continued well into the 1980s and early 1990s, lagging behind the phasing out of orphanages and children's homes. The first report, *Forgotten Australians* (Commonwealth of Australia, 2004), drew attention to children with disability in care and protection facilities, most frequently 'uncontrollable' girls and boys with intellectual disability in their adolescent years. Disability is also mentioned as a consequence of harsh treatment over time with disability in later life by wards of the state leaving 'care'.

### **2.3.2.2 Education for children with disability**

In contrast, and as early as the 1860s there had been schools for children who were deaf and blind, although these schools rarely accommodated children with intellectual disability or multiple disabilities. In 1929, the New South Wales Society for Crippled Children, founded by Rotary, opened its doors to care for children with polio or tuberculosis. Children lived in residential settings with school facilities, the most well-known being the Margaret Reid Home at St Ives and the Beverly Park Estate. Other children attended day only special schools.

By the late 1940s, parents of children with intellectual and multiple disabilities had come together to set up their own schools in the face of government resistance to their demands for education for their children. Taking New South Wales as an example, in 1946, a group of parents established the Subnormal Children's Welfare Association with the intention of sponsoring voluntary association schools. The

success of this initiative was such that by 1974, there were some 85 schools in New South Wales. Similar developments occurred across other Australian jurisdictions. Schools for children with intellectual disability and multiple disabilities were more likely to be parent-led and funded voluntary association schools. Schools for children with physical and sensory disability were more likely to be supported by public funding across all states and territories until the 1970s.

### **2.3.3 1960s and 1970s**

Through the 1960s and 1970s the Australian Government increased funding to charitable organisations for accommodation, employment (sheltered workshops) and other support services. A significant milestone in relation to families of children with disability was the introduction of the Handicapped Child's Allowance in 1974. This major policy mechanism was the first benefit paid to parents of a child with disability to encourage the care of children at home rather than in institutions. It followed the introduction, in 1968, of a benefit for handicapped children living in homes run by charitable organisations. This was known as the Handicapped Children's Benefit and was significant because it marked the entry of the Australian Government into the area of institutional care of children, previously a state responsibility (Lindsay, n.d.).

#### **2.3.3.1 Institutional care or family care**

During the 1960s and 1970s, the state became increasingly co-involved with families in providing care for family members with disability. There was a heavy policy emphasis in all jurisdictions on families caring for their children at home as a cost imperative: it was generally believed to be cheaper to support families to do the caring for those who would otherwise require expensive residential services (Llewellyn, Dunn & Fante, 1996). Notably, there was much less state concern at this time about children with disability already living in residential services as the forces driving de-institutionalisation had not yet taken hold.

Drivers in the international arena began to change perspectives on children with disability in Australia in the late 1970s. This first became apparent in relation to education for children with disability living at home, or attending charitable or privately owned schools, or in smaller health and disability institutions. The changes came later for children residing in the larger government health and disability institutions in which inmates who entered as children remained there as adults, joining others who had been placed there in late adolescence or early adulthood (NSW Department of Health 1983). The community was unaware that children 'put away' in large scale mental institutions had basic care only and little schooling or day activities.

#### **2.3.3.2 Education for children with disability**

Jurisdictions incorporated education for children with disability (later called children with special needs in the educational context) into government responsibilities on varying timelines across the country. The Australian Government's Karmel Report of

1973 recommended seven programs to remedy deficiencies in the Australian education system, one of which was to focus on special education. In 1974, as a result of the Karmel Report and with Schools Commission funding, the NSW Department of Education commenced a program of assuming responsibility for the operation of voluntary association schools. By 1982, 32 schools had been transferred with negotiations continuing for a further number (NSW Department of Education, 1982). Similar developments occurred in other Australian states and territories.

Seminal legislation enacted in the United States in 1975 (Education for All Handicapped Children Act 1975, PL 94-142) sparked intense discussion and debate in Australia. The legislation required all public schools accepting federal funds to provide equal access to education and one free meal a day for children with physical and mental disability. Public schools were required to evaluate handicapped children and create an educational plan with parental input that would emulate as closely as possible the educational experience of non-disabled students.

State government reports followed. For example, in May 1982 in New South Wales, a report on the deliberations of the Working Party on a plan for special education in New South Wales (NSW Department of Education 1982) was released, forging new directions in educating children with disability. Essentially, this plan gave children with disability, including those with profound and multiple disabilities, a place in the state-government education system. This more inclusive approach to educating children with disability took place as thinking about disability changed in Australia. The next twenty years were to see some 'new directions' come to fruition.

#### **2.3.4 1980s and 1990s**

Significant changes took place in the Australian Government's thinking about people with disability in this period. These changes played out rather differently for children than for adults with disability. By the early 1980s, state and territory governments were the major players in disability services encompassing education, health, family welfare, housing and transport. Non-government organisations delivered a wide range of services subsidised by Australian, state and territory governments (Lindsay n.d.).

From the late 1970s, the principle of normalisation began to influence thinking in Australia. This principle, initially articulated by Bengt Nirje from Sweden, states that people with disability should be assisted to establish patterns of life that are as close to or the same as those of society more generally. The normalisation principle as articulated by Wolf Wolfensburger (1972) was heavily promoted in Australia; later Wolfensburger added the term 'social role valorisation' to recognise the 'deep wounds' done to people with disability through institutionalisation.

The ideas of normalisation and social role valorisation found fertile ground in Australia. A series of reports in the late 1970s such as that from the Royal Commission into Human Relationships (Australian Government Publishing Service, 1977) reported significant shortcomings in disability programs and profound detrimental effects in segregating people with disability from the wider community. That said, there was little impact of these ideas initially for children with disability,

with the focus being on adults with disability in institutional care (NSW Department of Health, 1983). This occurred despite the number of inquiries into institutional care of children during these decades and the regular naming of hospitals/homes for children with disability in these inquiries (Swain, 2014).

Changes in Australian thinking about disability were also driven by the IYDP in 1981, complemented in the same year by national information on disability becoming available for the first time. This survey, *Handicapped Persons Australia 1981*, identified the number of people with disability, the nature of their disability, the services they needed and the extent to which these needs were being met. Of those determined to be severely handicapped, which was more than half a million persons (514,000) aged 5 years and over, more than one quarter of a million (271,000) were aged between 5 and 64 years of age. Of these 271,000, the vast majority – 244,000 (90 per cent) lived in households with only 27,000 (10 per cent) living in institutions (Australian Government Publishing Service, 1985).

Wen and Madden (1998) analysed this data from 1981 and following 10 years to investigate trends in community living over this time. They showed that by 1993 the majority (87 per cent) of people with severe handicaps under 65 years were living with relatives. Without underplaying the critical importance of the later de-institutionalisation period, these findings from the early 1980s through to the mid-1990s provide a timely reminder that the majority of individuals with disability – as children and as adults – lived at this time in the family home. This was despite their parents being advised – if the child's impairment was evident at birth - to put their disabled child away, forget about them and have another baby (Llewellyn et al. 1996). Archival research is needed to substantiate anecdotal evidence about the most likely age (if not at birth) that children with disability were placed in institutions in the mid-twentieth century. It appears likely there were two peak times; when younger siblings were born or when the child with a disability reached puberty and could not be managed in the family home (Llewellyn et al., 1996).

However, for those living in institutional care – the so-called mental institutions – the situation was dire. In New South Wales, this led to the Inquiry into health services for the psychiatrically ill and developmentally disabled in 1982, the report of which became known as the Richmond Report named after the Inquiry Chairman, David Richmond. This report recommended that institutions be closed progressively and that 'services be delivered primarily on a system of integrated community-based networks, backed up by specialist hospital or other services as required' (NSW Department of Health, 1983, p 10). This process is ongoing in New South Wales.

#### **2.3.4.1 New thinking – New directions**

In the international arena at this time (early 1980s) people with disability were organising themselves into self-help groups such as Disabled Peoples' International and similar groups in Australia followed suit. These self-help groups primarily involved people with physical disability or sensory disability, however in Victoria, a self-advocacy group for people with intellectual disability called REINFORCE began in 1982 and this organisation continues today (see <http://reinforce.org.au/>).

In 1983, the Australian Government established the Disability Advisory Council of Australia to provide direct advice about disability, and in 1985, the Office of Disability. Concerns about the situation of people with disability followed on from the IYDP, 1981, and led to a review of the Handicapped Persons Program. Writing in the foreword of the 1985 report *New Directions: The report of the handicapped programs review* (Australian Government Publishing Service, 1985), Senator Don Grimes noted that:

People with disability...have made it clear that they want to be treated as people first – people whose abilities matter more than their disability. They do not want to be seen as sick or different and they do not want all decisions to be made for them by other people. When given the opportunity, most people with disability respond positively to making major life decisions for themselves, assessing the risks involved and being prepared to make mistakes and learn from them. Increasingly, people with disability want a say, both in the development of programs designed to meet their needs and in the management of resulting services... (p iii).

This understanding of people with disability as people first, disabled second, represented a watershed in Australian Government thinking about disability (at least in relation to adults). This perspective of people with disability as 'responsible citizens' was in marked contrast to previous 'top-down' approaches based on medical understandings of disability. The intent now at Australian Government level was to move the policy focus from services and service providers to individual consumers (Lindsay, n.d.).

The introduction of the Disability Services Act (Cth) in 1986 was a direct response to the *New directions* report of 1983. The Act was accompanied by a statement of principles and objectives. The Act, based in a human rights framework, also recognised that people with disability have the same rights as do other members of society. This marked a significant turn in the official understanding of disability in Australia. The Act advocated, for the first time in Australia, for the 'least restrictive alternative' principle to assist people with disability to realise their individual potential. Disability services were to be integrated with mainstream services where at all possible complemented by a community focus for specialist services where these were considered necessary.

Pursuant to the Disability Services Act 1986 (Cth), state and territory governments were required to introduce or modify their legislation to conform to the Act's principles and objectives. At the same time, due to the lack of clarity about federal, state and territory government responsibility for disability services, the first Commonwealth-State Disability Agreement came into force in 1991. This five-year agreement attempted to rationalise government roles and responsibilities for the funding and operation of disability services and to develop a national, integrated disability services system.

While Australian Government developments during the 1980s primarily focused on disability services, the UN Declaration on the Rights of Disabled Persons in 1975 and the Royal Commission into Human Relationships in 1977 galvanised governments to action to secure basic human rights for people with disability in Australia. This led to



the Disability Discrimination Act 1992 (Cth) which provided protection against discrimination based on disability. It also aimed to promote equal opportunity and access for people with disability. This Act represented one more step in the lengthy process during which understandings of disability in Australia changed from disability as a health and charity issue (and later a welfare issue) to disability as a civil rights concern and shared community responsibility.

In the next section we discuss how and when this change in thinking came to include children with disability.

### **2.3.4.2 UN Convention on the rights of the child**

The UN Convention on the Rights of the Child (CROC) entered into force on 2 September 1990, and was ratified by Australia on 17 September 1991. As noted specifically in Article 1 (point 1), children with disability were to take their place with all other children:

Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

The potential impact of this could have been far-reaching. Article 23 specifically addresses children with disability. Point 1 of this Article decrees that in ratifying this convention:

Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community (Article 23, point 1).

However, our view is that there was little immediate impact for children with disability in Australia from the CROC. We suggest several reasons for this. There was an almost exclusive focus on adults with disability in legislative and policy frameworks; advocacy groups of people with disability were (almost by definition) comprised of adults with disability with many 'battles to fight'; parents of children with disability were primarily focused on getting better education and services, particularly early intervention, for their children; the current peak bodies advocating for children with disability such as Family Advocacy in New South Wales and Children and Young People with Disability Australia (CYDA) were in their infancy; and, young people with disability in institutional care had no voice – in contrast to the developing voice of young people leaving care through the CREATE Foundation, founded in 1993.

The Australian Government missed deadlines, or there were significant delays, in reporting on CROC. As noted in the *Consultation paper. Australia's performance on children's rights* (Llewellyn, personal papers, 2002) prepared by the National Children's and Youth Law Centre:

Australia's first report was due on 16 January 1993 but was not filed until December 1995 almost three years late. Its second report due in January

1998 has never been completed or filed. Its third report was due in January 2003 (to be completed). It is unlikely that Australia's third report will be considered by the United Nations Committee before late 2004. The consistent failure to meet reporting deadlines will mean that Australia will have avoided any scrutiny of its performance under CROC for nine years (p 2).

The Shadow report Part VI: Basic Health and Welfare, disability and the rights of the child in Australia (National Children's and Youth Law Centre and Defence of Children International, 2005) documented the significant gap between the claims of the government and the experiences of children with disability and their families. A useful analysis of Australian legislation relevant to CROC conducted by Clayton Utz Australia is available on the Australian Child Rights Taskforce website. The analysis with regard to Article 23 on children with disability can be found at <http://www.childrights.org.au/wp-content/uploads/2014/06/Article-231.pdf>

### **2.3.4.3 Changing perspectives on living arrangements of children with disability**

Planning for de-institutionalisation in Australia began in the 1960s and 1970s, however implementation did not occur seriously in the disability field until the mid to late 1980s and into the early 1990s, depending on the jurisdiction. Reform in child protection services had begun decades earlier as noted in a dedicated chapter on this topic in *Australia's Welfare 2001* (AIHW, 2001). Two systems had developed in Australia for children who could not live at home with their birth families. One was the health and (disability) system comprised of mental institutions and not-for-profit charitable homes as discussed previously. The other was the child protection system for those children at risk of or subject to child maltreatment.

Institutional care of children with disability frequently evokes a picture of confinement within secure boundaries and high walls: of children in bare and grim ward like hospital-type buildings under the watchful eye of ever-changing staff, often, but not always, separated from adults with intellectual disability or mental illness on the same institutional grounds. There is no doubt that this was the case in many institutions which housed children with disability in Australia and elsewhere. But not all institutional care for children with disability was in large 'mental' institutions. There were also smaller publically funded health facilities and charitable and privately owned facilities which attracted state, and depending on their regulatory status, Australian Government subsidies.

By the 1990s, residential environments for all children had expanded, many of which raised cause for concern. In jurisdictions around Australia there were many inquiries into residential care for children (Swain, 2014). In New South Wales for example, and under the Community Services Act 1994, the then Community Services Commission was responsible for reviewing the circumstances of children in care in New South Wales. During the 1990s the Community Services Commission conducted inquiries into residential and foster care, respite care, and juvenile justice among others. These inquiries led to the disclosure of unacceptable physical, social and emotional environments for children and specifically for children with disability in disability

specific and other children's facilities. For example, evidence of physical abuse including sexual abuse was clearly identified in two reports *Suffer the children: The hall for children report* (Community Services Commission, 1997) which resulted in this institution being forcibly closed and the *Inquiry into care and treatment of residents of Cram House – A service for the Illawarra Society of Crippled Children* (Community Services Commission, 1998).

Many of these inquiries drew attention to the presence of children with disability in facilities in sectors other than health, disability or care and protection. However, hard evidence was hard to come by. Recommendations such as the following from the *Just solutions – Wards and Juvenile Justice* report (NSW Community Services Commission, 1999) were common - 'To collect detailed and consistent data on the health and disability status of wards and other children and young people on entry into care and at regular intervals while in care' (p 31).

There was also growing recognition that children and young people with disability were among those who were homeless. Price-Kelly and Hill (1995), for example, noted the increase in young people with intellectual disability seeking assistance from agencies working with people who were homeless in inner city Sydney. In the National Evaluation of the Supported Accommodation Assistance Program in 1993, 11 per cent of the people using these services were those with a physical or intellectual disability.

In the 1990s state and territory government policies focused increasingly on community care. Community care policies were predicated on providing support to families with children with disability to continue caring for their children at home. This involved providing supports in the family home, as well as increased availability of respite, and incentives for mainstream services for children to include children with disability and appropriately meet their support needs. Institutional care was actively discouraged. By the mid-1990s however, concerns were being expressed in all Australian jurisdictions that parents were still seeking institutional care for their children. This was in complete contradiction of government policy which, in theory, had removed the option for families to seek residential care for children younger than 18 years of age.

Llewellyn and colleagues (1996) were commissioned by the then Commonwealth Department of Human Services to identify the reasons why families were seeking out-of-home care despite the growth in services and support to care for their children at home. Llewellyn et al. (1999) reported that of the 125 families who took part in this commissioned study, 75 per cent definitely did not want to place their child out of home, a further 19 per cent were undecided and 6 per cent were actively seeking or had already sought placement. Families actively wanted help to keep their children at home, however, in the absence of assured help departmental waiting lists for residential care became the 'norm'. Families were frequently being advised to put their child's name down on 'the list' from an early age to ensure they secured a place at a later time.

#### **2.3.4.4 Changing perspectives on education of children with disability**

In the early 1980s, the federal Schools Commission funded initiatives to support children with severe and profound disability, many of whom remained in institutional care. One of these was an Australia wide investigation to find children with disability not in school. Another was the setting up of a multi-disciplinary education and therapy team known as the Resource Support Unit in 1981 as part of the Severely Handicapped Children's Program, Division of Guidance and Special Education, NSW Department of Education. This team of six experienced educators and therapists which included Llewellyn (1982–83) developed resources, delivered training and supported teachers around the state so that children with severe disability could benefit from being in school. A third was the design, build and distribution of an innovative posture chair to enable children with severe disability to participate in classroom activities. Initiatives such as these held promise that children with disability would be welcomed – and appropriately supported – in educational settings.

In the late 1980s and early 1990s educational opportunities for children with disability expanded across Australia. The new opportunities included placement in mainstream classes with a modified curriculum or additional teaching support, small support classes in mainstream schools, and special schools for children who required more intensive support. The primary driver for government departments of education to include children with disability and offer a range of placements came from the Salamanca statement and framework for action on special needs education adopted by the World Congress on Special Education: Access and Quality in September, 1994 (UNESCO, 1994).

This groundbreaking document provided a major stimulus for change and the foundation for the inclusive education movement seen worldwide today. The guiding principle that informs this framework is that:

schools should accommodate all children [emphasis in original] regardless of their physical intellectual, social, emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote or nomadic populations, children from linguistic, ethnic or cultural minorities and children from other disadvantaged or marginalised areas or groups (p 6).

Noteworthy here is that children with disability are considered to be part of all children as per the CROC.

The Salamanca Statement and Framework for Action is considered seminal for its offerings of over 80 detailed points of action for principles, policy, and practice in special needs education. It came less than one year after the UN Standard Rules for the Equalization of Opportunities for Persons with Disability (UN, 1993) adopted by the General Assembly at its 48th session on 20 December 1993. These 22 rules summarised the key messages that had developed through the decade of the World Programme of Action, during which the human rights perspective in relation to people with disability had begun to crystallise. The Standard Rules represented a strong moral and political commitment of governments to take action to attain equalisation of

opportunities for persons with disability. However, this was not a legally binding instrument, serving primarily as an instrument policy-making and as a basis for technical and economic cooperation. (It was to be more than a decade later before the UN General Assembly adopted the CRPD on 13 December 2006.)

## 2.4 2000s onwards

On 13 December 2006 at the United Nations Headquarters in New York the Convention on the Rights of Persons with Disability (CRPD) and its Optional Protocol were adopted and subsequently opened for signature on 30 March 2007. There were 82 signatories to the Convention on that day, including Australia. Australia ratified the Convention and its Optional Protocol on 17 July 2008. The Australian Government and Disabled People's Organisations (DPOs) in Australia played a key role in the negotiations and framing of the CRPD, which in turn, gained wider community awareness of the shortcomings in Australian legislation, policy and practices affecting the everyday lives of people with disability and their families and carers.

The Australian Government then looked to the National People with Disability and Carers Council to provide expert advice and information on the development and implementation of a national disability strategy. The main thrust of their endeavours was to hold conversations and consultations around Australia with people with disability and their families. The resulting report, *Shut out: The experience of people with disability and their families in Australia* (Commonwealth of Australia, 2009b), recorded for the first time in one place and under the auspices of the Australian Government's advisory body the serious shortcomings in Australia with regard to the disadvantage and inequities facing people with disability in all areas of life: in health, education, social life and being part of the community. Thus began the era of the national disability reform agenda.

### 2.4.1 The national disability reform agenda

The first component of the national disability reform agenda was the National Disability Agreement introduced by the Council of Australian Governments (COAG) in 2009. This agreement proclaimed nationally agreed objectives and outcomes for people with disability, their families and carers and set out the roles and responsibilities for national and state and territory governments for the provision of disability services for people with disability. This replaced the previous Commonwealth-State Disability Agreements (CSDAs).

The public centrepiece of the national disability reform agenda was the National Disability Strategy 2010–2020 (NDS) (Commonwealth of Australia 2011a). This was developed under the auspices of COAG to take Australia forward to 'achieve full inclusion of people with disability in everyday Australian life' (p 13). The strategy was based on three fundamental understandings of disability which clearly expressed, for the first time, a coherent and inclusive approach toward disability in Australia.

The first of the three imperatives – the human rights imperative – is drawn from the understanding that people with disability are citizens, not objects of charity (Commonwealth of Australia 2011a, p 16). The second of the three is the social imperative. This is drawn from the findings of the Shut Out report documenting the widespread rejection and exclusion of people with disability in mainstream Australian society. The final, economic imperative is drawn from the recognition of the benefits to society of encouraging ‘workforce participation and building human capital’ (Commonwealth of Australia, 2011a, p 19).

A further focus was the development of an evidence base to support the national disability reform agenda. The *National Disability Research and Development Agenda* (NDRDA) (Department of Social Services, 2011) was released in November 2011. The broad aims of the *National Disability Research and Development Agenda* were to:

facilitate the creation of a comprehensive evidence base and the foundations of robust research that will inform policies and practices of the disability sector, governments and the mainstream community. (NDRDA, 2011, p 4)

Attached to this agenda was a funding commitment made specifically to support the delivery of the objectives and reform priorities of the National Disability Strategy and the National Disability Agreement. The Audit of Disability Research in Australia (Centre for Disability Research and Policy, 2014) found that the evidence base on disability in Australia was not fit for purpose in relation to the national disability reform agenda and the research that existed was difficult to find.

In 2011, the Productivity Commission recommended the setting up of a national insurance disability scheme and a national injury insurance scheme. The former attracted bipartisan support at the federal level. The stage was then set for corraling state and territory support for a national disability insurance scheme and introducing the necessary legislative changes at federal and state and territory level. The National Disability Insurance Scheme Act 2013 (as amended) came into force on 1 July 2014. This occurred almost 30 years after similar legislative changes at the state and territory levels were driven by the introduction of the national Disability Services Act in 1986.

#### **2.4.2 Exclusion of children with disability**

Australian disability legislation, policy and strategy frameworks and implementation plans are now aligned with international best practice in rights, active citizenship and social responsibility. However in our view these remain focused on adult persons with disability, as was the case nearly 30 years ago with the state and territory legislation that followed the Disability Services Act 1986. One example comes from the NSW Law Reform Commission (1999), which opined that the New South Wales Disability Services Act 1993 required amendments to adequately apply to the needs of children and young people.

More recently, New South Wales introduced the Disability Inclusion Act on 4 December 2014 to replace the earlier Disability Services Act 1993. In this legislation,

children with disability receive two mentions. The first mention is point 12 of section 4, General Principle, which states: '(12) The needs of children with disability as they mature, and their rights as equal members of the community, are to be respected'. The second mention is in section 5, Principles Recognising the Needs of Particular Groups. Point 5 of this Act is inserted here in full:

- (5) Supports and services provided to children with disability are to be provided in a way that:
  - a) recognises that a child with disability has the right to a full life in conditions that ensure the child's dignity, promote self-reliance and facilitate the child's active and full participation in family, cultural and social life, and
  - b) recognises that children are more vulnerable to risk of abuse or exploitation, and
  - c) addresses that right and risk, and ensures the best interests of the child is the primary concern in making decisions affecting the child while also respecting the responsibilities, rights and duties of a parent or other person legally responsible for the child in relation to giving appropriate direction and guidance for the child's welfare, and
  - d) respects the views of the child with disability (having regard to the child's age and maturity).

### **2.4.3 Disability as a risk factor in care and protection frameworks**

Disability in care and protection frameworks in Australia is presented as a risk factor. This is clearly seen in *Protecting Children is Everyone's Business National Framework for Protecting Australia's Children 2009–2020* in which one of the 'known risk factors for abuse and neglect' is 'childhood disability, mental health/behavioural problems' (Commonwealth of Australia, 2009a, p 21).

In New South Wales, the Department of Family and Community Services (FACS) makes publicly available a large number of documents in relation to child protection. So for example there is the FACS/Community Services (n.d.) Care and protection practice framework and the FACS/Community Services (2006). Child wellbeing and child protection – NSW Interagency Guidelines and the FACS/Community services (n.d.) and Joint Investigation Response Teams (n.d.). Similar documents are available for child protection policies and guidance in the care and protection sector and for service personnel in the disability sector, for example, *Child protection guidelines: What ADHC staff need to know about child protection* (FACS/ADHC 2014). In some states and territories there are also informative publications for parents of children with disability in relation to protecting children and young people with disability (for example, Government of South Australia, 2013). Overall these documents, in our view, continue the 'tradition' of regarding disability primarily as a risk factor.



The disability as a risk factor approach was helpful in the past in drawing welcome attention to maltreatment of children with disability in institutional contexts. The downside is that this disability as risk approach is not in line with Australia's international obligations or national legislation. It also hinders robust data collection and the empirical evidence needed to understand which children with disability, in what contexts, under what circumstances and to what extent are most likely to be at risk of sexual abuse. Fundamental to developing this understanding is regarding disability as only one component in children's lives.

## 2.5 Shape of the current disability service system and policies and practices

A challenge in answering Research Question 1 on understandings of disability in Australia and how these have changed over time is to what extent these understandings represent the everyday circumstances of Australian children with disability. As we have shown, the focus in Australian legislation and policy is on persons with disability as adults. This has important ramifications for how children with disability are regarded in service system policies and practices. Internationally, authors have also drawn attention to how disability legislation is framed in relation to assuming persons with disability are adults (Sabatello, 2013). This creates several difficulties.

The first is that although children with disability may receive separate mention this is most frequently in relation to family and support of their families. We suggest there are three presumptions present in this approach: the first is children with disability are 'special' and the disabled dependants of families and carers; the second that families will act in their children's best interests; and the third is that the family is the fundamental unit to be supported. These presumptions are clearly seen in two relevant UN Conventions. The Preamble to the Convention on the Rights of the Child 1993 states that 'the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community' (p 1). In CRPD just over a decade later (2006): 'the family is the fundamental group unit of society and as such is entitled to protection by society and the State' (CRPD, Preamble, para. X). Both conventions also take a 'special' approach to children with disability: Article 23 of CROC primarily takes a 'special needs and circumstances' approach to the rights of children with disability; in CRPD, one article – Article 7 – is devoted to children with disability.

However commendable the intention, there is some Australian evidence that families do not always act or are not always able to act in the best interests of their children. Children with disability are proportionally over-represented in care and protection proceedings and matters of reportable conduct. In the late 1990s research in New South Wales demonstrated that children with disability were over-represented in care and protection caseloads and care matters. The study examined over 407 care

matters finalised in two New South Wales Children's Courts over a nine-month period from May 1998 to February 1999 and reported that 24 per cent of all children had an identified disability or medical condition (McConnell, Llewellyn & Ferronato, 2000).

Recently the NSW Ombudsman (2016) noted that over one-quarter – 29 per cent (588) – of notifications of reportable conduct (time period 1 July 2013 to 30 June 2015) were children with disability or additional support needs. Further it was noted that FACS reports that 12 per cent of children in out-of-home care have a disability however 36 per cent of all closed notifications of reportable conduct matters from this sector involve a child with a disability. The NSW Ombudsman noted similar over-representation (although not quite so high) in the reportable conduct matters from the school sector. The New South Wales government school sector reports 12 per cent of children in schools have a disability. However, 21 per cent of the notifications from this sector involve children with a disability. Reports of over-representation of children and young people with disability in the out-of-home care sector come from other jurisdictions in Australia (CREATE, 2012). In our view, up to date national studies are certainly warranted on the prevalence of children with disability in care and reportable conduct matters.

To be clear these figures do not equate with prevalence or relative risk of child maltreatment for children with disability. Rather what the data illustrate is that, as a group, children with disability appear at a higher rate in the out-of-home care sector than expected according to their presence in the population. The proportion of children with disability (0-14 years) in the general population is on average 6.1 per cent (3.4 per cent in 0-4 age range and 8.8 per cent in 5-14 age range, ABS, 2012). As noted by the NSW Ombudsman (2016) children with disability are in the range of 21-29 per cent in reportable matters, and 24 per cent in finalised care matters. Overall these New South Wales figures are just over four times higher than the presence of children with disability at 6.1 per cent in the total child population.

### **2.5.1 Quality and safeguards**

Relevant to this discussion paper and the changing shape of disability support and services is an outstanding and ongoing concern about ensuring adequate quality and safeguards for people with disability. There are two aspects of concern to policy makers, advocacy groups, researchers and people with disability and their families and carers. The first is to ensure adequate quality and safeguards for individuals with disability who are eligible for the National Disability Insurance Scheme (NDIS) (Robinson 2014). The second is to ensure adequate quality and safeguards in the changing balance of responsibilities from the specialist disability sector to mainstream services. The responsibilities of each with regard to the NDIS and state and territory government responsibilities are set out in the COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems, 27 November 2015 (available at [https://www.coag.gov.au/sites/default/files/Schedule\\_I-Principles\\_determine\\_responsibilities\\_NDIS\\_other\\_service\\_systems.PDF](https://www.coag.gov.au/sites/default/files/Schedule_I-Principles_determine_responsibilities_NDIS_other_service_systems.PDF)).

Four points are critical here in our view. The first is that currently state and territory governments have responsibility for specialist disability services, some of which are

contracted out to the non-government sector. Those remaining are directly funded by and under the control of the relevant state/territory government. With full NDIS roll-out occurring from July 2016, state and territory governments will no longer hold responsibility for specialist disability services. (The timing of this varies somewhat across the country depending on the Heads of Agreement between the Commonwealth and State/Territory government).

In New South Wales for example, the Department of Family and Community Services, Ageing, Disability and Home Care recently announced (5 May 2016) the process to tender out its disability services to the non-government sector. This is described thus: From July 2018, the NSW Government will no longer provide specialist disability supports or basic community services. Services currently provided directly by the NSW Government will be transferred to the non-government sector. This means that after July 2018 there will be no disability services provided by the NSW Government. This raises concerns for peak advocacy groups about safeguards for people with complex needs including independent advocacy/decision support, monitoring by the Ombudsman, and establishing 'provider of last resort' arrangements.

The second point is that there are many people with disability in the community who do not currently access specialist disability services. There are many possible reasons for this including services not being accessible where they live; long waiting lists particularly for early intervention services in heavy demand urban population areas; services restricted to people with certain types of impairment and /or level of severity; unwillingness to disclose their disabling condition; and fear or dislike of service interventions in their lives.

Approximately 460,000 of the nearly 4 million persons with disability in Australia will be eligible as participants in the NDIS and within this number a proportion will be eligible for a funded support package. The choice and control principle underpinning the NDIS means that eligible participants will be able to source their supports as they wish. This raises concerns about adequate safeguarding in this so-called 'market economy' for services and supports.

However the NDIS is not only about eligibility for a support plan and, for some participants, a funded support package. It is also predicated on Australian society changing to become inclusive and welcoming of people with disability in all aspects of community life. The third point therefore in the disability reform agenda is the requirement for all mainstream services – education, criminal justice, health, transport, housing and so on – to be inclusive, welcoming, appropriate and safe for people with disability. This raises the question of safeguarding and accessible and appropriate complaints mechanisms for people with disability in these mainstream sectors.

The fourth point is the exponential increase in workforce required to accommodate the increase in people with disability being served by the NDIS when fully implemented. In February 2016, the Queensland Office of Public Advocate released a report titled *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland* (2016). This report states that in Queensland alone the number of people with disability served under the NDIS will more than

double from 45,000 to 97,000, requiring an additional workforce of 13,000 people. The difficulty in recruitment and retention of a quality workforce in the disability sector is well documented in Australia (for example, see work by the Community Services and Health Industry Skills Council available at:

<http://www.cshisc.com.au/develop/quality-case-studies/industry-spotlight-case-studies/recruitment-and-retention/> ).

Specific issues frequently mentioned include a lack of quality induction, and ongoing training requirements and opportunities to undertake professional development.

Overall the national disability reform agenda constitutes large scale social reform. It is about reform of disability services. More than that, the major part of the reform agenda is to change community attitudes about people with disability in Australia so that all Australians are treated as equal and contributing citizens.

The focus of this reform agenda is not new however. Just on 30 years ago the Disability Services Act 1986 was introduced, based on a vision of an inclusive and respectful Australia. Five years ago the National Disability Strategy 2010–2020 set out a vision to achieve ‘an inclusive Australian society that enables people with disability to fulfill their potential as equal citizens’ (2011, p 22), noting in particular the need for an improved mainstream response. There is much current activity focused on how to maintain quality and ensure safeguards for people with disability in this changing and desired landscape of Australian society. This comes from the National Disability Insurance Agency (NDIA) in consultation papers, public forums and consultations reports; from federal and state statutory agencies responsible for safeguarding the rights of individuals with disability, for example the Commonwealth Ombudsman, the NSW Ombudsman, the Victorian Disability Discrimination Commissioner and the Royal Commission into Institutional Responses to Child Sexual Abuse; from peak advocacy bodies such as Children and Young People with Disability Australia, People with Disability Australia, Women with Disability Australia and the NSW Council for Intellectual Disability among others.

Particular projects have also been instigated for example by National Disability Services (NDS) in the roll-out of its national program Zero Tolerance: A Framework to prevent and improve sector responses to abuse, neglect and violence experienced by people with disability. This program aims to provide evidence-based resources to safeguard the rights of people with disability. There is particular concern about whether the current regulatory frameworks and oversight bodies in states and territories in relation to people with disability will continue to function alongside any future Commonwealth oversight body or mechanisms.

As well as concerns, opportunities have come to light with the roll-out of the NDIS. These have provided cause for reflection in some quarters on Australia’s obligations under the CRPD. As the report of the Australian Law Reform Commission into Equity, Capacity and Disability in Commonwealth Laws (2014) points out at 10.75:

As a national quality and safeguards system for the NDIS is being developed by COAG, the ALRC considers it desirable for state and territory governments to review their disability services legislation, with a view to reform that is consistent with the National Decision-Making Principles and the

Commonwealth decision-making model. This might involve, for example, moving towards compliance with the CRPD, as well as preparing for the implementation of the NDIS. (ALRC 2014, p 288)

To date to the best of our knowledge there has not been similar reflection on Australia's obligations to children with disability under the CROC.

## **2.5.2 Assumptions which underpin responses to sexual abuse of children with disability**

Earlier in this discussion paper, two competing understandings on disability were presented. The first is the rights and social responsibility understanding which underpins the national disability reform agenda. The competing understanding frames disability as deviance from the norm, as negative difference whereby individuals with disability are 'othered' in many ways, one of which is being thought to require technical, medical health responses which are outside the responsibility of society more generally. Stigma, discrimination and social isolation also contribute to othering children with disability. This process of othering as argued by Robinson (2012) leads to children with disability being on the one hand more vulnerable to maltreatment including sexual abuse and on the other hand to disinterest in abuse of children with disability and less being done to prevent abuse occurring or responding appropriately after the event. A similar argument has been made by Frohmader, Dowse and Didi (2015) for Women with Disabilities Australia (WWDA) and others internationally with regards to women with disability (WHO, 2014).

In our view, if children with disability were regarded as children first, with disability regarded as only one aspect of their lives, they would have a strong presence in policy frameworks designed to keep all Australian children safe. One would expect to see explicit detailing of the ways in which societal attitudes play out in the institutional contexts frequented by children with disability and the ways in which these children may be at potential risk of maltreatment including sexual abuse. This is not the case.

### **2.5.2.1 Non-normalised institutional contexts for children with disability**

As noted in Section 1, children with disability spend a great deal of time in a range of institutional contexts. Some of these institutional environments are not 'normalised'. This means that the only children present will be those with disability, for example in situations such as respite care, Special Olympics, classes for children with disability, and school transport. In many contexts, there may be one adult or very few adults unrelated or not known to the child. This creates an environment in which there is little oversight of adult or older peer behaviour. There is concern that this situation where adults are unknown to children – and to each other – will increase with the expanding and increasingly casualised workforce in the disability sector with the NDIS market reforms.

The second instance of non-normalised environments is where adult assistance is required with daily intimate care for children with disability. In this situation the child's body is regularly handled by non-familial adults. Often there is only one adult present, who may be of different gender to the child. Two potential outcomes may arise. The first is that children with disability in this situation have less opportunity to develop a sense of their bodily integrity and what constitutes acceptable touch. At the same time, their vulnerability to sexual abuse is increased when the attending adults believe that children with disability would not know what was right or wrong and in addition would be unlikely or unable to report any wrongdoing (Martinello, 2014; Stalker & McArthur, 2012). As suggested in the literature on sexual abuse of adults with disability, these circumstances can lead to a reframing and renaming of what would be called sexual abuse in relation to children without disability as acceptable behaviour in the minds of both perpetrators and others present (Frohman, Dowse & Didi, 2015).

Recognising the particular everyday circumstances of children with disability would also mean taking into account what is known about the likely behaviours of children with disability under duress and particularly those with communication difficulties. There is for example a well-developed evidence base on the so-called 'challenging' behaviours of individuals with disability. These behaviours are now understood to be primarily driven by physical, health, emotional and sensory stressors and need to be treated accordingly (Emerson & Einfeld, 2011).

## SECTION 3 Interactions that influence the risk of sexual abuse of children with disability in institutional contexts

- In Australia we have to rely on international data for prevalence rates of sexual abuse against children with disability. In a meta-analysis in the Lancet, Jones et al. (2012) reported that the pooled prevalence rate of sexual violence against children with disability was 13.7 per cent (range <1.0 per cent– 40 per cent).
- Because there is no Australian empirical data, the Australian grey literature relies on organisational collective knowledge or anecdotal information to document assumed prevalence and risk.
- Jones et al. (2012) reported a 2.88 risk ratio for sexual violence against children with disability. This means that children with a disability as a group have a 2.88 times higher risk of sexual violence than children who do not have a disability.
- The scientific and grey literature note risk factors for sexual abuse of children including those with disability can be setting related: physical condition, policies and procedures, training of staff and organisational culture.
- There is an urgent need for Australian data on prevalence and risk of sexual abuse of children with disability and on how characteristics of a child's impairment and their environment interact in ways that influence their risk of sexual abuse in institutional contexts.

### 3.1 Overview

There is no empirical Australian data available to answer Research Question 2 on how characteristics of a child's impairment and their environment interact in ways that influence the risk of sexual abuse of children with disability in institutional contexts.

This is a critical question to answer specifically in relation to children with disability for three reasons. First, children with disability differ from their non-disabled peers because they spend time in disability-specific institutional contexts such as respite care, school transport, Special Olympics or school classes for children with disability.



In these contexts there may only be one or very few adults present; it is unlikely that any non-disabled children are present.

Second, children with disability may be thought of as ‘other’, and particularly so in disability-specific settings. Practices and behaviours that are neglectful or abusive may be reframed in these contexts as ‘acceptable’. Although this ‘othering’ of people with disability may be thought to belong to an earlier era, there is good evidence in Australia that this continues today. This is clearly demonstrated in the reports of the Senate Inquiry into Involuntary or Coerced Sterilisation of People with Disability in Australia (Commonwealth of Australia, 2013) and the Senate Inquiry into 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 (Commonwea of Australia, 2015).

Third and highly relevant to this section is that children with disability are children first and foremost with disability being only one, although an important component of their lives. As with all children, we need to consider various child-related characteristics such as age, gender, family and socio-economic circumstances and their family and community environments and the interaction of these components to understand the risk of sexual abuse.

### **3.1.1 Multiple, interacting factors**

It is highly unlikely that one single factor is responsible for increased risk of sexual abuse of children with disability. It is more likely there are multiple interacting factors. The presence of multiple interacting factors in risk of maltreatment for children is a live topic in the broader child maltreatment literature. An Australian example speaks to the dangers of presuming there is one particular risk factor. This comes from Hunter and Price-Robertson’s (2012) paper on Family structure and child maltreatment. Do some family types place children at greater risk? The authors point out that it is often believed that the sole parent family structure is a risk factor for child maltreatment. Even if there was evidence of association between sole parent families and maltreatment, association does not mean causation. Furthermore, association may be mediated by other factors. In other words, just because sole parent families appear more frequently in care and protection proceedings this does not mean that this family structure causes child maltreatment. There is a dangerous leap – or slippery slope – between observing frequency and then believing that frequency equals cause. The authors summarise thus:

much of the perceived relationship between family structure and child maltreatment can be explained by factors such as poverty, substance misuse and domestic violence...maltreatment reflects the effects of multiple, dynamic, interrelated and, often, cumulative risk factors. (p 1)

Regrettably a more nuanced understanding of the risk of sexual abuse of children with disability is not yet available. The overall perception is that it is disability *per se* which causes maltreatment. This perception is driven by misinterpretation of prevalence and risk figures which suggest a higher likelihood (frequency) of sexual

abuse for children with disability. This comes from falling into the trap of thinking association means causation; overlooking potential mediating factors; and ignoring the multiple, dynamic, interrelated and often cumulative risk factors that may be present.

### 3.1.2 Overlooked factors

One factor 'conveniently' ignored is to differentiate disability that predates sexual abuse from disability caused by sexual abuse. As demonstrated in the *Forgotten Australians* report (Commonwealth of Australia, 2004) disability is one consequence of child maltreatment over an extended period of time. There is very little discussion of this in the scientific and Australian grey literature on children with disability and child maltreatment.

Another overlooked factor is the setting in which the sexual abuse took place. Thus, even though there are studies of sexual abuse of children with disability in school or in hospitals for example, these studies are not about abuse which occurs in those settings. The institutional contexts of hospital or school have been convenient settings for sourcing samples of children to study prevalence and/or risk. Further difficulties with the evidence on sexual abuse of children with disability are explained after the findings section.

A further difficulty is the limited resources directed to research in this field resulting in a poor evidence base and a small body of researchers focusing on the topic. This can be seen particularly in the lack of research which connects abuse of children with disability with broader child abuse research (Robinson, personal communication, July 2016).

## 3.2 Conceptual framework

The conceptual framework for this section comes from the Australian standard definition of disability. To recap, disability results from the interactions between individuals, their impairment and societal barriers. Ideally, the scientific literature would provide answers to questions about characteristics and person-environment interactions in relation to sexual abuse. That is not the case yet even about violence and adults with disability as noted by Hughes et al. (2012) in their systematic review of this topic for the World Health Organisation (WHO) reported in the *Lancet*.

With an increasing number of population surveys and administrative data sets which include people with disability, there are now more opportunities to examine characteristics, interactive effects and comparative differences for people with disability and their non-disabled peers. An Australian example comes from Krnjacki et al. (2015a), which analysed secondary data from the Personal Safety Survey (ABS, 2012) of more than 17,000 adults to estimate the population-weighted prevalence of violence (physical, sexual, and intimate partner violence and stalking/harassment) in the previous 12 months and since the age of 15. The survey

data allowed for investigation of many (although not all) critical components: age, gender, type of violence, comparison with non-disabled peers, and longevity of exposure. Using a cross-sectional design for a similar purpose, Emerson et al. (2015b) analysed secondary data from Wave 3 of the UK Understanding Society survey. There were additional advantages in this data set including individuals' perceptions of safety and their socio-economic circumstances. These types of population data sets and research designs are needed in Australia to investigate the prevalence and risk of sexual abuse for children with disability and to examine the person–environment interactions which exacerbate or diminish this risk.

The implementation of the Child Protection National Minimum Data Set (AIHW, 2014) is a welcome beginning. Unit record data reliably recorded in each jurisdiction is needed however to ensure a useful, robust and reliable data set. The in-principle agreement for jurisdictions to include the disability identifier must be implemented as soon as possible. Otherwise Australia will have to continue to rely on international evidence. This is a second best approach, especially when we understand that settings can be very different in the countries that produce the research data. In our view, it is critically important that Australia has its own data from which we can derive evidence-informed approaches to preventing sexual abuse of children with disability.

### **3.2.1 Difficulties in relying on international data**

Having Australia's own data is even more important when we realise that it may take some time before the international literature incorporates the individual characteristics and person–environment interaction perspective. There are several reasons for this. The first is because the predominant view of disability *per se* as the risk factor for child sexual abuse means that researchers have tended not to 'look any further'. A second reason is that in the past less attention has been given to population surveys and administrative databases for children. Australia now has national frameworks in disability and in child protection that require this to change (Commonwealth of Australia 2011a, 2009a).

A third is the ethical and other challenges in child self-report in surveys/administrative databases which have been overcome in other countries for example the National Longitudinal Survey of Children and Youth in Canada (<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4450>). A fourth reason is that children with disability are frequently excluded from population and/or administrative data collections because they are considered unreliable or inaccurate respondents. This is no longer acceptable because of Australia's international obligations under CRC and CRPD. International initiatives such as UNICEF's Global Partnership on Children with Disability (<http://www.gpcwd.org/>) and UNICEF Multiple Indicator Cluster Surveys (<http://mics.unicef.org/>) provide direction to ensure detailed and robust data collection of matters pertinent to children happens worldwide.

We now turn to reporting on prevalence and risk estimates and then analyse the relatively limited evidence on characteristics and their interaction effects. To align with other materials from the Royal Commission into Institutional Responses to Child

Sexual Abuse, this section uses a format similar to that in Kaufman and Erooga's report on *Risk Profiles for Institutional Child Sexual Abuse: A literature review (2016)*. This section sets out to answer the question: What are the risk and protective factors for children who are at increased vulnerability to sexual abuse in institutional contexts? First we report on child factors, followed by a discussion of family factors and then environmental contextual factors.

## 3.3 Search methods

This section describes the methods used to examine the scientific and the grey literature in relation to risk and protective factors for sexual abuse of children with disability in institutional contexts.

### 3.3.1 Scientific literature

The search used, as the seminal reference document, the first international systematic review and meta-analysis of observational studies on violence and children (aged  $\leq 18$  years) with disability by Jones et al. (2012). This research was commissioned by the WHO and reported in the *Lancet*. The time period for reports of studies in Jones et al. (2012) was 1 January 1990 to 17 August 2010. Accordingly, our search strategy did not return to pre 2010 studies.

The inclusion criteria for the Jones et al. (2012) were: cross-sectional, case control or cohort design; violence perpetrated against children ( $\leq 18$  years); specific disability type, specific disorders, activity limitations or support needs reported; definitions and methods of measurement for violent outcomes reported; and reported prevalence rates, odds ratio or raw data to enable calculation of prevalence.

The exclusion criteria were: studies based on selected populations affected by violence (for example, children with disability referred for problems related to sexual abuse); focus mainly on adults ( $> 18$  years); and response rate  $< 50$  per cent or not reported.

Sixteen of the 17 studies included in Jones et al. (2012) addressed sexual violence (authors' term).

To identify studies reported since the August 2010 cut-off date for Jones et al. (2012) we conducted a Web of Science and Scopus citation report of their study. This revealed an additional three studies which also met the Jones et al. (2012) inclusion and exclusion criteria. These were Butler (2013), Devries et al. (2014), and Mueller-Johnson et al. (2014). Hand searching of the reference list of these three studies identified one further study by Turner et al. (2011). This resulted in 20 studies to be analysed: 16 from Jones et al. (2012) and four studies since that time.

### 3.3.2 Grey literature

The grey literature was sourced from four topic areas: child protection; family violence; disability; and criminal justice. The scope of literature sourced was intentionally broad given the intersections between these topics and the lack of material specifically addressing children with disability. We included grey literature which referred to disability within a broader focus on health in addition to sexual abuse. Grey literature was sourced online using the cut-off date of 2006 in line with the introduction of CRPD and relevant Australian inquiries. Reference lists of the grey literature identified were hand searched.

Searching began online using the four topic areas. This yielded six reports which addressed maltreatment of children in institutional settings, children with disability in institutional settings, and papers on the specific needs of people with a disability including women and children. From these seven papers: Woods (2008), Robinson (2012, 2016), Bromfield and Holzer (2008) and reports from People with Disability Australia (PWDA) and Commonwealth of Australia (2009, 2011), a further 13 reports were identified.

Of the 20 articles analysed for this discussion paper, seven were published or funded by Commonwealth agencies, seven were funded by state governments, and the remaining five produced by national peak disability bodies. Fifteen of the 20 were specific to disability alone.

## 3.4 Description of literature

Prior to reporting the outcomes of the analysis of the literature, we provide a brief explanation of the terms 'prevalence' and 'risk'. Prevalence is distinct from incidence. Prevalence is a measurement of all individuals affected by a condition at a particular time, whereas incidence is a measurement of the number of new individuals who develop the condition during a particular period of time. Prevalence can be described as lifetime prevalence, point prevalence or period prevalence. For example abuse at the point of time the data was collected would be point prevalence. This is quite different to abuse over a period of time. In Emerson et al. (2015a) we sourced data on prevalence at two time periods: over the last 12 months and since 15 years of age. This is a standard way of investigating whether the abuse is only recent (last 12 months – period prevalence) and/or over a much longer period of time. Lifetime prevalence is self-explanatory – how many individuals at any time over whatever is considered their lifetime. Jones et al. (2012) refer to lifetime prevalence. In their meta-analysis six studies recorded prevalence as lifetime, one in the past year; in three studies the time period was not specified (1) or not recorded (2).

Risk is distinct from prevalence. Risk is a measurement of the likelihood at a population level that a particular condition, in this case sexual abuse, will occur. This does not mean every person in that population (in this case, children with disability) will be at the same level of risk. This is because risk is estimated across the entire population of children with disability and compared to the risk for children without

disability (relative risk). As we have noted above, risk is influenced by child characteristics, impairment, personal factors and environmental factors and the interactions between these. Future studies which use secondary analysis of population surveys and administrative data sets will be in a better position to identify what differences in risk levels exist if any, why and for whom.

The Australian grey literature on sexual abuse of children with disability relies heavily on citation of selected studies from the international scientific literature. The authors/studies cited most frequently are Sobsey (1994), Sullivan and Knutson (1998, 2000), American Academy of Pediatrics (2000) and Jones and colleagues (2012). When citations are provided there is usually also commentary suggesting that the findings from other countries would be replicated in the Australian context.

In this section we use the language and terms used in the studies discussed: some of these are not used in Australia or may be considered unacceptable. The scientific and grey literature has been combined to provide a presentation of the key issues that also offers robust insight into the significant complexities of the available literature. Analysis of the research design, primarily in relation to the scientific evidence, precedes discussion on what was reported specifically on prevalence and risk. Study limitations include recruitment or selection of participants (Spencer et al. 2005), disability inclusion by diagnostic type (Turner, 2011) and sample size which is noted throughout this section.

## **RESEARCH DESIGN**

The studies included in Jones et al. (2012) used a range of research designs. These include: two cohort studies (Benedict et al., 1990; Spencer et al., 2005); the remaining were 14 cross-sectional.

The type of research design favours particular findings. The strongest research design utilises population data from the entire population or a specified sample (for example, random, representative and stratified). This design also provides the opportunity to examine between- and within-group differences. That is, if the population was children and young people, say, between 5 and 18 years, then children with disability could be compared to their peers without disability (between-group) and differences among children with disability and among their non-disabled peers could also be examined (within-group). The differences to be examined are limited only by items available in the survey. In designs which do not have a comparison group of children without disability, findings are limited to within-group data on the children with disability and cannot be generalised beyond that particular group.

The study by Spencer and colleagues (2005) was the only study included in Jones et al. (2012) that used a whole population data set. These authors used a UK birth cohort which was regularly updated throughout childhood and was then linked to a child protection register. Using a whole population data set eliminates sample selection bias. The findings of this study showed the association between specific disabling conditions and child abuse registration. The risk for registration of child abuse was 7.65 times higher for conduct disorder and 6.38 times higher for moderate/severe learning difficulties when adjusting for birthweight, gestational age,

maternal age and socio-economic status. The risk estimates reported in Jones et al. (2012) were unadjusted.

Most of the studies in Jones et al. (2012) and the four additional studies used random or population samples of school students in which disability could be identified (Alriksson-Schmidt et al. 2010; Blum et al. 2001; Devries et al. 2014; Everett Jones et al. 2008; Miller 1993; Mueller-Johnson et al. 2014; Sullivan & Knutson 2000; Suris et al. 1996). Studies which reported findings from random samples of children or families were Butler (2013), Cuevas et al. (2010), Jemta et al. (2008) and Turner et al. (2011).

Convenience or specific-setting samples of children with disability were used by Ammerman et al. (1994), Mandell et al. (2005), Sullivan et al. (2000) and Reiter et al. (2007). For example, the Ammerman et al. (1994) study sample were children admitted to a psychiatric hospital providing a service for children with developmental disabilities. While convenience sampling of children attending a particular setting allows understanding of children in that setting, it militates against comparisons with children in other settings.

The rigour with which authors describe their study designs also varies. For example there is no description of how the samples were derived in Ebeling and Nurkkala (2002), who investigated child psychiatric inpatients and in Verdugo et al. (1995), who investigated children in institutional care.

## **SAMPLE SIZE**

The sample sizes of children with disability in the 16 studies in Jones et al. (2012) ranged from 41 (Ebeling & Nurkkala, 2002) to over 5,500 (Blum et al., 2001). This is a wide range; generally speaking the larger the sample size the more likely the findings are not by chance alone. Caution needs to be exercised when interpreting statistical significance with small sample sizes.

## **RESPONDENTS**

Studies vary by respondents who provided the information on disability and sexual abuse. What counts as disability may vary considerably when disability is observed, determined by clinical judgment or by standard measures. In reporting extreme circumstances such as sexual abuse retrospective reports are known to present some difficulties. Proxy reports, for example by parents, may deliver different results to reports from the child or young person who has been harmed.

The most frequently occurring respondents across the 20 studies were children themselves, followed by their caregivers, official records/professional reports, with reports by professionals being the least frequent.

Ten studies: Self-report by questionnaire or interview (Alriksson-Schmidt et al., 2010; Blum et al., 2001; Butler 2013; Devries et al., 2014; Everett-Jones & Lollar, 2002; Jemta et al., 2008; Miller, 1993; Mueller-Johnson et al., 2014; Reiter et al., 2007; Suris et al., 1996)



Five studies: Official records or professional reports (Benedict et al., 1990; Ebeling & Nurkkala, 2002; Spencer et al., 2005; Sullivan et al., 2000; Sullivan and Knutson, 2000)

Two studies: Interviews with caregivers (Ammerman et al., 1994; Mandell et al., 2005)

Two studies: Caregiver interviewed if child very young (<10years) and child interviews if >9 years of age (Cuevas et al., 2010; Turner et al., 2011)

One study: Questionnaire by professionals (Verugo et al., 1995)

## **COMPARISON GROUP**

There was no comparison group in seven studies (Ammerman et al., 1994; Benedict et al., 1990; Ebeling & Nurkkala, 2002; Jemta et al., 2008; Miller, 1993; Sullivan et al., 2000; Turner et al., 2011).

In the remaining 13 studies, comparisons between children with and without disability were reported. Stronger designs utilise a comparison group which is from the same overall sample. Ten studies used comparison groups from the same data set or sample. For the other three studies different methods were used: Miller's (1993) comparison group was recruited from participating public schools in the district; Reiter and colleagues (2007) asked children with disability to 'bring a friend' for the comparison group; and although Verugo et al. (1995) stated non-disabled children, there was no source reported.

## **CONFOUNDING VARIABLES**

Studies need to account for potential confounding variables. Confounding variables are variables/factors that may influence the relationship between disability and sexual abuse. Researchers can only control for variables that are in the data set – for example, socio-economic status, neighbourhood and parental mental health. Studies which controlled for potential confounders were Alriksson-Schmidt et al. (2010), Benedict et al. (1990), Butler (2013), Cuevas et al. (2010), Devries et al. (2014), Everett-Jones and Lollar (2008), Spencer et al. (2005), Mandell et al. (2005), Mueller-Johnson et al. (2014) and Turner et al. (2011).

When studies controlled for socio-demographic and family factors (Turner et al., 2011; Spencer et al., 2008), the association between violence and disability was reduced. For example, Turner et al. (2011) examined sexual victimisation among children with physical disability, internalising psychological disorder, ADD/ADHD (Attention deficit disorder/Attention deficit hyperactivity disorder) and developmental/learning disorder. Initial analyses showed that children with any (of the four) disorders, as well as physical disability and internalising psychological disorder reported significantly higher rates of sexual victimisation. When factors such as ethnicity, age, gender, socio-economic status, number of parents in the house and parental psychological disorder were controlled for in the analyses, only internalising psychological disorders was shown to be a predictor of sexual victimisation. This is quite a different finding to that which occurred before controlling for those variables.

In other words, only the children with internalising psychological disorder (compared to children with no disability) had greater odds of experiencing sexual victimisation. Devries et al. (2014) investigated three child factors: age, working outside the home and having mental health difficulties. The report identified that these risk factors were similar for young people with disability as well as their non-disabled peers, suggesting that there may be a factor or factors common to the risk of violence for all children over and above the disability variable.

The recent study by Mueller-Johnson and colleagues (2014) used data from a US national school-based survey (n=6,749) to investigate sexual victimisation among physically disabled youth and controlled for 17 socio-demographic, lifestyle-related and family/parenting-related factors. Findings revealed physical disability was a significant predictor of (contact and non-contact) sexual victimisation for boys and not for girls.

When population data is available it is possible to account for at least some potential confounding variables. The current state of evidence suggests that disability may not be the risk factor *per se* that it is believed to be. This is a critical finding which needs to inform population and targeted prevention and intervention approaches. This finding mirrors those being reported in other disability research using population data with control of variables such as Emerson et al. (2015a) and Emerson et al. (2015b). Llewellyn and Hindmarsh (2015) recently reported findings of diminished risk (against usual expectations) in a review of population based studies on pregnancy and birth outcomes and child protection for parents with and without intellectual disability.

## 3.5 Findings

### 3.5.1 Prevalence

Jones et al. (2012) reported the pooled prevalence rates of sexual violence at 13.7 per cent (range <1.0 per cent– 40 per cent) from 15 out of 16 studies addressing sexual violence in their meta-analysis of 17 studies on violence against children with disability. The 16th study which addressed sexual abuse – Spencer et al. (2005) – did not report prevalence.

Note that the range of these pooled prevalence rates is extreme. The range is from less than 1 per cent of the population of children with disability to 40 per cent of this population. The reason for this extreme range is the substantial heterogeneity of these studies. This means that although all studies met the inclusion criteria for the meta-analysis, the studies were not alike, thus the pooling of the prevalence rates brings together rates from studies which were different on several dimensions. Given the substantial heterogeneity between the estimates in the 15 studies and the possibility of small sample size study effects, Jones et al. (2012) calculated a fixed-effect estimate which for sexual violence resulted in a lower pooled prevalence estimate of 8.9 per cent (95 per cent CI 8.4–9.3). This rate is likely to be closer to the 'true' prevalence estimate.

The studies differed with respect to research design including the way participants were sampled, sample size, the person providing the information or how potential confounding variables were controlled and whether there was a comparison group. Definitions of disability and sexual abuse also differed between studies. Each of these is discussed in detail below.

The additional four studies since Jones et al. (2012) reported prevalence rates within the range in their meta-analysis. These were: 18.3 per cent in Butler (2013), 7.1 per cent for boys and 23.6 per cent for girls in Devries et al. (2014), 22.35 per cent in Mueller-Johnson et al. (2014) and 9.0 per cent in Turner et al. (2011). We were not able to calculate risk from these studies.

In the absence of Australian empirical evidence on prevalence and risk, the grey literature also relies on organisational collective knowledge or anecdotal information collected through membership enquiries. This is not surprising. As noted in *Protecting children is everyone's business. National Framework for protecting Australia's children 2009-2020* (Commonwealth of Australia, 2009) 'there is no robust data on child abuse and neglect on incidence/prevalence' (p 11). Specifically speaking about disability, Robinson (2012) noted that 'it is difficult to discuss the rates of prevalence of abuse and neglect of children and young people with disability with any certainty' (p 12). Jackson, Waters and Abell (2015) noted 'There is even less data available regarding the prevalence of people with intellectual disability who have experienced trauma' (p 56).

Prevalence of maltreatment of children with disability in the Australian grey literature is most frequently cited as being three times (3.14–3.4) more likely in comparison to their non-disabled peers (Robinson, 2012; Children with Disability Australia, 2015; Australian Cross Disability Alliance, 2015). Robinson (2012) stated a prevalence figure of around three times higher based on findings from Sullivan and Knutson (2000). This figure is relative risk not prevalence. As noted in Sullivan and Knutson (2000) 'disabled children were 3.4 times more likely to be the victim of some type of maltreatment than their nondisabled peers, a risk factor coefficient...' (p 1268). The prevalence rate reported by Sullivan and Knutson (2000) is 31 per cent for children with disability and 3 per cent for their non-disabled peers.

To put this in perspective, Jones et al. (2012) reported pooled prevalence estimates (from 16 studies) of 13.7 per cent (9.2–18.9) from a total of 1,455 incidents in 14,675 children. The prevalence range from the 15 studies was from <1 per cent to 40 per cent. Citing the prevalence rates from individual studies is less helpful than citing prevalence rates from a meta-analysis, for all the design limitations mentioned above. This is because in a meta-analysis samples are pooled, allowing for more powerful statistical techniques to come closer to an estimate of true prevalence. Note carefully however the detailed discussion in Jones et al. (2012) of the limitations of the individual studies and therefore of their meta-analysis, which however remains the most robust available in the scientific literature to date.

The Australian grey literature also refers to factors mentioned in the international literature that may affect reporting of sexual abuse of children with disability. Three documents are relevant here. Submissions from National Disability Services (2015), Robinson et al. (2015) and Robinson (2016) all note that abuse may be under-

reported. Reasons given include parents and others not pursuing criminal justice proceedings; children with disability being regarded as unreliable witnesses; and, disability services staff at all levels being unaware of or overlooking incidents that constitute sexual abuse.

### 3.5.2 Risk

Jones et al. (2012) estimated the risk of sexual violence for children with disability using 10 out of 16 studies. The relative risk ratio was 2.88. This means that children with a disability as a group have a 2.88 times higher risk of sexual violence than children who do not have a disability. Jones et al. (2012) caution against a one size fits all interpretation of this figure because this is an estimated risk figure derived from only 10 heterogeneous studies. What this means is that the best risk estimate available at this time is 2.9 (2.88 rounded) times higher for children with disability than for non-disabled children.

Jones et al. (2012) were able to calculate risk specifically for one impairment group only, those with mental/intellectual disability. They calculated this risk as 4.6 times higher than for children without disability (n=732). It was not possible to estimate risk from the four additional studies identified for this discussion paper.

There is limited mention of risk characteristics related to children with disability in the Australian grey literature. Rather 'disability' is presented as the stand-alone risk factor for child maltreatment (Bromfield and Holzer, 2008; COAG, 2009; Senate Community Affairs Reference Committee, 2015; Wood, 2008). There is however mention of risk circumstances – for example, 'factors that increase risk' (Robinson, 2012, p 7) and 'drivers for abuse' (NDS, 2015), noting that 'impairment does not of itself make a child or young person vulnerable' (p 3). Robinson (2012) noted that 'other features in young people's environments, relationships and the cultures of their communities may have a greater part to play in how vulnerable (or otherwise) children with disability are to abuse and neglect than does their impairment' (p 12) . This is welcome and in line with international understandings of disability in ICF (WHO, 2013) and CRPD (UN, 2006).

Other risk factors in relation to disability and the risk of sexual victimisation were mentioned in the grey literature:

- children with disability who require assistance with intimate care activities (Commonwealth of Australia, 2011; Robinson, 2015);
- children and young people who require behaviour modification or management (Frohman and Sands, 2015);
- children who 'live or spend significant time in settings where they are expected to be always compliant and well behaved' (Robinson, 2012, p 12); and
- children with communication, speech difficulties or high behavioural support needs (CYDA Submission, 2015).

### 3.5.3 Heterogeneity

Study heterogeneity is critical to understanding the strength of the prevalence estimates. Stoltenborgh et al. (2011) is the largest meta-analysis of combined prevalence figures of childhood sexual abuse to date. These authors included data from 217 publications (1980-2008) which included 331 independent samples with a total of 9,911,748 participants. They also reported heterogeneity. Jones et al. (2012) in similar fashion were at pains to point out the limitations of their meta-analysis.

#### **DISABILITY – DEFINITION AND MEASUREMENT**

Which disability was investigated and how this was defined and measured varied across the scientific studies. Most studies examined multiple disabilities (for example, physical and intellectual and psychological). A few studies examined a single disability, for example, Ammerman et al. (1994): developmental disability; Mandell et al. (2005): children with autism; Miller (1993): behavioural disorders; Verdugo et al. (1995) and Reiter et al. (2007): intellectual disability.

Disability was identified by self/parental-report (for example, Alriksson-Schmidt et al. 2010), standardised measures/instruments (for example, Butler, 2013), and diagnoses contained in administrative records (for example, Ebeling & Nurkkala, 2002).

#### **SEXUAL ABUSE – DEFINITION AND MEASUREMENT**

Sexual abuse definitions also varied and in the following ways:

- unwanted sexual touch (Cuevas et al., 2010; Reiter et al., 2007; Suris et al., 1996)
- forced involvement in sexual acts (Alriksson-Schmidt et al., 2010; Blum et al., 2001; Cuevas et al., 2010; Everett-Jones & Lollar, 2008; Jemta et al., 2008; Suris et al., 1996; )
- intercourse before 12 years (Blum et al., 2001)
- noncontact (no physical contact with abuser) and contact sexual abuse (Mueller-Johnson et al., 2014)

Seven studies used items from existing or purposefully developed instruments to measure sexual abuse. For example, Juvenile Victimization Questionnaire (Cuevas et al., 2010; Mueller-Johnson et al., 2014; Turner et al., 2011); International Society for the Prevention of Child Abuse and Neglect Child Abuse Screening Tool and selected items from the WHO Multi Country Study on Women's Health and Domestic Violence against Women (Devries et al., 2014); Child Abuse and Neglect Interview Schedule (CANIS) (Ammerman et al., 1994).

Eight studies asked the respondent (child or caregiver) a specific question or questions about sexual abuse (Alriksson-Schmidt et al., 2010; Blum et al., 2001; Butler 2013; Everett-Jones et al., 2008; Jemta et al., 2008; Mandell et al., 2005; Reiter et al., 2007; Suris et al., 1996). Examples include: 'have you ever been sexually assaulted or raped?'; 'intercourse before 12 years of age?'; 'unwanted sexual touch, forcing to touch someone sexually?'

The remaining five studies obtained the measurement of sexual abuse from existing records (for example, child protection records) (Benedict et al., 1990; Ebeling & Nurkkala, 2002; Sullivan et al., 2000; Sullivan & Knutson, 2000; Spencer et al., 2005).

### **3.5.4 Child characteristics**

#### **DISABILITY TYPE**

Jones et al. (2012) reported mental/intellectual disability with a higher risk of sexual violence (4.62) compared to all other violence/maltreatment (any maltreatment risk, 4.28; physical violence, 3.08; emotional abuse, 4.31). This apparent higher risk may be partly influenced by the low number of studies on children with physical, sensory and other impairments, such that pooled data could not be analysed.

Turner et al. (2011) included different forms of disability: physical disability, internalising psychological disorder, ADD/ADHD and learning/developmental disorders. Using the National Survey of Children's Exposure to Violence (USA) and controlling for socio-economic and parental factors, there was elevated risk of sexual victimisation only for those with internalising psychological disorders. Sullivan and Knutson (2000) defined nine disability types: visual impairment, hearing impairment, speech/language, mental retardation, behaviour disorder, learning disability, health impairment, autism and physical. When comparing risk of sexual abuse for children by disability type compared to non-disabled children, there was an increased risk of 3.14. Specifically, for autism, no increased risk; children with visual and hearing impairment slightly greater risk (both 1.2); learning disability, 1.8; health impairment, 2.0; physical, 2.0; with speech/language difficulties, 2.0; mental retardation, 4.0; and behaviour disorder, 5.5.

#### **SEVERITY OF DISABILITY**

Children with disability are most often treated as a homogenous group in prevalence and risk studies without level of impairment being recorded. Those with more severe/profound impairments may have been excluded from the studies. For example, Mueller-Johnston et al. (2014) in their national school-based survey of adolescents did not include children who attended special needs schools. Additionally, any study which relies on self-report and phone interviews (such as Turner et al., 2011) is most likely to exclude youth with severe developmental disability. Suris et al. (1996) required 169 questions to be completed in 50 minutes, thus minimising the opportunity for participation by those with significant intellectual impairment.

The only study which attempted to understand disability by functional characteristics comes from Benedict et al. (1990). The authors examined level of functional characteristics – feeding, dressing, and toilet training as delayed vs age appropriate. Their findings suggest 'marginally' functioning children may be at greater risk than

the 'more impaired' for maltreatment (not specifically sexual abuse), contrary to their expectations. The study has significant limitations however including small sample size and specific setting (53 children with disability in a hospital treatment program cross-matched with a state abuse register). Of these 53 there were sexual abuse reports for three of the children.

## **AGE**

Jones et al. (2012) reported insufficient data available from the included studies to calculate an adjusted odds ratio by age. Of the studies that considered age, there is varied evidence on the influence of this child-related factor. Sullivan and Knutson (2000) compared age ranges of children with disabilities and reported that preschool age children with disability experience significantly more sexual abuse than children with disability in elementary, middle school and high school age groups.

Two studies report conflicting findings, that is, that younger children with disability are at lower risk of sexual abuse. Alriksson-Schmidt et al. (2010) reported ninth grade female students with a range of disabilities were at significant lower risk of being forced to have sexual intercourse than 12th grade students. Similarly, Turner et al. (2011) reported the odds of sexual victimisation increased with age for children with physical, internalising psychological disorders, ADD/ADHD or development/learning disorders.

## **GENDER**

The influence of gender has been examined in two ways: Comparing disabled girls with non-disabled girls (between group differences); and disabled boys vs disabled girls (within disability group differences). This leaves out between group comparisons for non-disabled children by gender with comparisons between disabled children by gender.

When examining disabled vs non-disabled maltreated children, Devries et al. (2014) reported that disabled adolescent girls self-reported nearly twice as much sexual violence as that reported by non-disabled girls (23.6 per cent vs 12.3 per cent). There were no significant differences in reports of sexual violence between the two groups of boys. Suris et al. (1996) examined differences in reporting the experience of sexual abuse by adolescents with visible and non-visible chronic health conditions, using data from the Minnesota Adolescent Health Survey. Both girls and boys with non-visible chronic health conditions were significantly higher than controls (non-disabled girls and boys) in reporting a history of sexual abuse. In contrast, there were no significant differences for girls as well as boys with visible chronic health conditions compared to the control groups of girls and boys without chronic health conditions.

Mueller-Johnson et al. (2014) reported gender results comparing disabled girls with non-disabled girls. Findings showed boys with physical disability nearly three times more likely to suffer (lifetime) contact sexual victimisation than able-bodied boys. Girls with physical disability were 1.4 times more likely to experience lifetime non-contact sexual victimisation than able-bodied girls, however they were not more likely



to experience (lifetime) contact sexual victimisation. The odds ratios for past-year victimisation were largely similar to lifetime victimisation for both boys and girls.

Two studies compared sexual abuse for disabled girls vs. disabled boys. Sullivan and Knutson (2000) reported that among maltreated (sexual, physical, sexual/physical, and emotional) children with disability, significantly more girls than boys were victims of sexual abuse. Similarly Turner et al. (2011) reported lower odds of sexual victimisation for males relative to females when controlling for a range of factors including ethnicity, age, gender, socio-economic status, number of parents in the house and parental psychological disorder.

### **3.5.5 Family factors**

If family factors are considered in the studies, the factors vary considerably. For example, number of parents in the household, parenting practices, inter-parental violence, socio-economic status and parental mental health.

Mueller-Johnson et al. (2014) examined gender differences with regard to family factors. For example, boys with physical disability were more likely to come from single parent families, to have fewer friends, be involved in violent behaviour, less likely to experience warm parenting, more likely to experience harsh parenting and to be exposed to inter-parental violence. For girls with physical disability there were no significant differences except higher exposure to harsh parenting. When controlling for risk factors for the overall sample (girls and boys), gender was a predictor of sexual victimisation, with girls with physical disability having a higher risk than boys with physical disability. When analysing boys and girls separately predictors of sexual violence showed different patterns for boys and girls. For boys physical disability remained a significant risk factor for both contact and non-contact sexual victimisation when other risk factors were controlled for. However for girls physical disability was not a predictor.

One study, Benedict et al. (1990) noted above, reported an association between maltreatment and children with unmarried parents, parents with fewer years of formal education and those who lacked stable employment in that these children were more likely to have substantiated reports. The limitations of these findings come from the study being small numbers, and about all maltreatment as there only 34 records and only three children sexually abused. As Hunter and Price-Robertson (2012) noted, there are significant limitations in using child protection data.

### **3.5.6 Environmental context**

#### **COUNTRY**

The evidence base on prevalence and risk of sexual abuse for children with disability is primarily drawn from studies conducted in high income countries, specifically the United States and the WHO European region. The exception to this is the study from Uganda by Devries and colleagues (2013). In this study, secondary data analysis of

baseline data from a school-based intervention program revealed the prevalence of sexual violence of disabled children (aged 11-14) as higher (males 7.1 per cent; females 23.6 per cent) than for their non-disabled peers (3.8 per cent males; 12.3 per cent females). These prevalence rates are within the range found in the meta-analysis by Jones et al. (2012). The lack of evidence from low- and middle-income countries should be addressed as these countries have been noted to have higher population rates of disability and higher levels of violence (WHO, 2011). This is echoed in the UNICEF Global Partnership on Children with Disabilities Child Protection Task Force Literature Review Paper (2015).

## **SETTINGS**

Regrettably for the purpose of this discussion paper we could not locate empirical evidence on the impact of settings on the prevalence of sexual abuse for children with disability. As noted above the primary way in which settings are used in the scientific literature is as recruitment/sample sources. So, for example Jones et al. (2012) reported higher estimates of prevalence of all types of maltreatment including sexual violence in the studies which recruit participants/respondents from hospital settings. This is not surprising given that hospital settings include children who are attending in relation to identified clinical concerns. Devries et al. (2014) reported that the school environment was the main venue at which violence is occurring. However this related to differentiation between perpetrators of violence. That is, the study used a sample of young people from a school setting and then categorised and compared instances of violence from parents, from female peers, male peers, from other.

The grey literature in contrast to the scientific literature does focus attention on institutional settings. These include out-of-home care (Woods, 2008), educational settings (Robinson & McArthur, 2014), safe spaces for women and children (including those with disability) escaping violence (Senate Community Affairs Reference Committee, 2015), and generalist services available to children and families where children with disability are present (Commonwealth of Australia, 2009).

For example, the report of the Senate Community Affairs Reference Committee (2015) noted that submissions to their inquiry –

showed that a root cause of violence, abuse and neglect of people with disability begins with the devaluing of people with disability. This devaluing permeates the attitudes of individual disability workers, service delivery organisations and most disturbingly, government systems designed to protect the rights of individuals. (p xxvi)

## **3.6 How risk is understood in the grey literature**

The current focus on person-centred care in disability services (ACT NDIS trial 2015) identifies potential risk circumstances at the individual level as well as addressing

quality assurance safeguards with respect to service providers. The National Disability Services submission (2015) to the Royal Commission into Institutional Responses to Child Sexual Abuse identified that the NDIS will –

see increased delivery of services to people in environments that are hard to regulate, such as people's own homes or community settings. Such environments may offer increased opportunity for abuse and exploitation of vulnerable individuals and reinforce the need to build safeguards into the system at all levels to minimise risks. (NDS 2015, p 2)

Segregation of children and young people with disability from mainstream settings is another recurrent theme in the grey literature. This is particularly so for children with cognitive disability and for those with communication difficulties. This is mentioned by 3 out of the 20 reports examined for the purposes of the present discussion paper. For example, Robinson and McArthur (2014) in *Safe at school? Exploring safety and harm of students with cognitive disability in and around school* drew attention to the potentially reduced capacity of children with cognitive disability to share concerns about abuse and neglect, including sexual abuse, or their fears about speaking up. These factors may exacerbate the potential for abuse as perpetrators may rely on children not 'telling'. In segregated settings where there is little external oversight, organisational cultures may develop where staff are not encouraged (or are actively discouraged) from speaking up and children not believed when they do speak up. It is also important to note that for those students with high support needs whose voices need to be heard in the research, creative research methods are required to ensure the potential communication difficulties of the child do not inhibit the sharing of information about safety and abuse and neglect.

Earlier, French, Dardel and Price-Kelly (2009) reported increased potential for abuse when adults and children with cognitive impairment shared the same spaces in an institutional setting. For example, concerns are noted by French et al. (2010), CDA (2015), Robinson (2012) and Robinson and McGovern (2014) about safe settings in education including school transport for those children and young people where there is likely to be only one adult not related or unknown to the child passengers.

Robinson (2015) noted that existing environmental and structural levels within the community perpetuate the abuse of children with disability. Robinson (2015) went on to state that circumstances within an organisational context may exacerbate or perpetuate abuse for children with disability. Kaufman and Erooga (2016) noted that risk factors for children including those with disability can be defined as 'setting-based', with factors such as physical condition, policies and procedures, training of staff and organisational culture contributing to prevalence and risk of sexual victimisation for children with disability.

Robinson's (2012) review of scientific literature noted the correlation between high-risk environments where violence and exploitation are common features and a culture of closed communication that can exacerbate risk. One strategy is to make available information that sexual abusers may target those with 'impairment issues' or 'those reliant on others for assistance' (Government of South Australia 2012, p 5).

The grey literature draws attention to two concerns about the scientific literature. The first issue is the lack of inclusion of the voices of children with disability in prevalence and risk data (Senate Community Affairs Reference Committee 2015; Robinson 2012). This provides an example of how children with disability – in contrast to non-disabled children – are not regarded as active agents in their own right. Just as for all children, giving voice to the lived experience narratives of children and young people is critical to understandings of risk and also critically to understanding the impact of harm (Save the Children, Handicap International, 2011).

The second issue is that critical analysis is required about why disability *per se* continues to be thought of as the determining factor in the lives of children and young people in relation to their risk of maltreatment. As authors in the grey literature comment, this is entirely out of kilter with the official understanding of disability in Australia and national legislative, governance and policy frameworks addressing the lives and circumstances of people with disability in Australia. In our view, it is time to move on from attributing risk for children with disability only to their disability and to focus attention on institutional settings, the people in those settings, and effective governance, safeguarding and quality mechanisms.

## **SECTION 4 Key factors in the prevention of sexual abuse of children with disability in institutional contexts in the future**

- There is little scientific evaluation of programs and prevention strategies for sexual abuse of children with disability.
- Robinson (2012) argued for the development of 'protective frameworks, which actively and specifically work to prevent harm' (p 28).
- Prevention strategies identified fall into four categories: strategies for the child, for the family/carer, for staff/managers and for organisations.
- Strategies for children and families promote education relating to safe touching, protective behaviours and recognition of behaviour that might indicate abuse.
- Strategies for staff and organisations focus on policy and procedures: reporting concerns, training staff, and challenging the culture of silence that historically has surrounded this issue.
- Some international organisations are currently attempting to map international evaluations of prevention strategies, the results of which could be applied to the Australian community.

### **4.1 Overview**

Our approach in this section was to identify the most robust evidence available from the international literature, to identify knowledge gaps and to consider how international findings may inform prevention approaches in Australia in the future. This is critical given that we could not identify any Australian effectiveness or evaluation studies on prevention of sexual abuse for children with disability in institutional settings.

### **4.2 Conceptual framework**

The conceptual framework employed here takes a situational approach consistent with best practice in the field of prevention of sexual abuse of children. This situational prevention framework developed initially by Kaufman (2005) comes from

situational crime prevention theory. Kaufman et al. (2012) later aligned this framework more closely with institutional settings. The relevance here is that over and above consideration of child, family and community, the framework specifically incorporates characteristics of the setting. This framework points to five institutional level components. These are: target locations, physical environment, facilitators, lifestyle and routine activities, and organisational climate and local community influences. The framework offers a systematic way to analyse institutional contexts for all children many of which also include children with disability. It is also useful for considering disability-specific institutional contexts.

## 4.3 Search methods

### 4.3.1 Scientific literature

We were unable to locate a meta-analysis or systematic review of effectiveness of interventions for sexual abuse of children with disability. We turned to the recent systematic review by Mikton et al. (2014) on interventions to prevent violence against persons with disabilities as the reference document for sourcing scientific literature. The Mikton et al. (2014) review analysed the effectiveness of different types of interventions. The review period covered January 2000 to August 2011. Inclusion criteria were: universal, selective or indicated intervention; sexual violence, child maltreatment, youth violence, intimate partner violence and elder maltreatment; physical impairments, sensory impairments, mental health conditions or intellectual impairments; intervention compared with no intervention or service as usual; distal or proximal outcomes; and, any study design except surveys of participant satisfaction. The authors conducted searches of electronic databases, hand searches of specific journals and reference lists of review articles, and communication with experts in the field. Ten studies were identified.

Of these 10, only one study focused on sexual abuse for children with disabilities (Bowman et al., 2010). Seven were about adults with disabilities, one on physical abuse only and one addressed child maltreatment without specifying sexual violence.

To identify additional literature we conducted a Web of Science and Scopus citation report for Mikton et al. (2014). No additional studies were identified which focused on sexual abuse and children with disability. Therefore we undertook a search of Web of Science databases. We used the following search terms: *disab\**; *handicap\**; *impairment\**; *child\**; *youth*; *young*; *young people*; *young person*; *adolescen\**; *sexual abuse*; *sexual violence*; *child maltreatment*; *sexual assault*; *youth violence*; *sexual victimization*; *sexual exploitation*; *intervention*; *prevention*; *training*; *governance*; *regulation*; *legislation*; *evaluation*; *program*; *curriculum*; *pilot*.

We refined the output of this search to 'review articles' publications and 2011-2016. Two were located: McEachern (2012) and Wissink et al. 2015. Hand searches of the reference lists of these two review papers revealed no additional intervention/prevention studies since 2011, the latest date included in Mikton et al.

(2014). One additional program evaluation by Lee & Tang (1998) was identified in a recent Cochrane Systematic Review (Walsh et al. 2015) on school-based programs for the prevention of child sexual assault.

### **4.3.2 Grey literature**

The search strategy began with the key reports of Robinson (2012), COAG (2009), Kaufman and Erooga (2016) and submissions to the recent Senate inquiry into Domestic Violence in Australia (Commonwealth of Australia 2015 at [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Finance\\_and\\_Public\\_Administration/Domestic\\_Violence/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Finance_and_Public_Administration/Domestic_Violence/Report)). We also conducted a Google search using the search term 'evaluation of child sexual abuse prevention programs'. The output was further refined by 'disability' and then by 'Australia'. Searches of websites of peak disability advocacy bodies, the peak disability services body (National Disability Services) and statutory agencies were also undertaken. Hand searching of reference lists from identified reports was also conducted.

These search strategies for the grey literature yielded 25 documents addressing prevention strategies for sexual abuse potentially relevant to children with disability. Text of all documents was searched to identify mention of disability. Two documents were Australian evaluation outcome reports (UNSW 2010; 2014). Four provided commentary on factors relevant to evaluation (Commonwealth of Australia 2009; Robinson 2012; Robinson & McGovern 2014; Commonwealth of Australia 2015). The remaining 19 documents included program descriptions or practice recommendations, of which 15 were Australian. The remaining four documents were sourced from the international grey literature to supplement the small quantum of Australian materials.

## **4.4 Understanding prevention strategies and evaluation**

In the first section we report on the small evidence base of evaluation of programs and prevention strategies from the scientific and grey literature. We supplement this with analysis of the recommendations suggested in the literature sourced for Research Question 2 on prevalence and risk of sexual abuse of children with disability.

### **4.4.1 Evaluation studies**

The two evaluation studies found in the analysis of the available scientific literature were Bowman et al. (2010) and Lee & Tang (1998). The results of the evaluation of the intervention programs in these studies are presented in the Appendix Table 1.

The first program targets the individual with disability. Using a randomised control method, Lee and Tang (1998) evaluated the effectiveness of Wurtele's (1990)



Behavioral Skills Program with a group of Chinese female adolescents (11-17 years) with mild mental retardation. This program teaches self-protection skills and has been used successfully with preschool age children from high income countries (for example, Wurtele 1990). It covers seven safety rules, one personal body safety rule and four self-protection skills. Safety rules include: we are the boss of our bodies; location of private parts; when is it acceptable to touch your own private parts; when is appropriate for doctors/nurses/parents to touch children's private parts; otherwise it is wrong to have private parts touched/looked at; it is wrong to be forced to touch others private parts; inappropriate touching by others is never the child's fault. The personal body safety rule was 'It's not okay for a bigger person to touch or look at my private parts (unless they need help as in situations when their private parts get hurt' (Lee & Tang 1998, p 108). The four self-protection skills: verbal response; movement responses; telling trusted persons; reporting. The program delivered to the control group covered safety skills unrelated to sexual abuse. Post program delivery the intervention group showed greater knowledge of sexual abuse and self-protection skills as well as recognition of appropriate/inappropriate touch requests. Not all knowledge was maintained at two-month follow up.

The second program (Bowman et al., 2010) targeted developmental disabilities service providers. The program aimed to evaluate a prevention workshop on service providers' knowledge and attitudes concerning sexuality (including sexual abuse) of persons with developmental disabilities (55 per cent of the individuals served by the practitioners attending this program were below 18 years). The four hour workshop covered content such as definitions of sexual abuse, reporting laws, statistics and patterns of sexual abuse, and risk factors. This was followed by identification and how to respond to sexual abuse. Finally the workshop covered content such as risk reduction, changing attitudes and prevention programs/curricula. The pre/post evaluation of the workshop showed a significant although small increase in knowledge related to sexual abuse. There was no significant change in the participants 'global perception' or attitudes about people with developmental disability. The authors recommend introducing more intensive programs with follow-up.

We were not able to locate in the Australian grey literature any evaluation or effectiveness/efficiency studies on programs for prevention of sexual abuse of children with disability in institutional contexts. The National Framework for Protecting Australia's Children (COAG, 2009) offers differentiated approaches to address child maltreatment. This is laudable however differentiated approaches require effectiveness and cost efficiency studies to determine which are effective for whom, to what extent and under what conditions. The gap in evaluation studies severely limits the capacity of the sector to provide evidence-based prevention programs.

Robinson (2012) in a grey literature report discussed this lack of empirical evidence in the field of child disability and maltreatment including evaluation of prevention and intervention approaches. She noted that in order to make significant changes in the lives of children with disability, development of 'protective frameworks, which actively and specifically work to prevent harm' (p 28) are required. Recently in work exploring school as an institutional setting, Robinson and McGovern (2014) again noted the lack of evidence-based materials for children with disability, their families and carers

to understand risk including sexual risk and lack of access to evidence-based prevention approaches. This is a critical gap in knowledge which hinders the commitment to and development of prevention programs to address the heightened risk of sexual abuse experienced by children with disability. Due to the lack of specific materials for children with disability we turn now to evaluation of child protection frameworks for all children.

Two of the 25 reports located in the Australian grey literature evaluated programs based in New South Wales. Both evaluations acknowledged vulnerability and risk for particular groups of children including children with disability. The earliest, an evaluation of Brighter Futures (Hilferty et al, 2010) used a survey design and a cross-sectional analysis of at-risk families to investigate the efficacy of the intervention. This report noted that both parental and child disability present a more complex picture and require different engagement and response than are typically used with families with young children. Thus, the authors reported the evaluation findings may not be 'relevant to families who have a child with a disability because traditional parenting programs were inappropriate' (p 133).

The evaluation of the New South Wales Care and Protection Framework, Keep Them Safe (UNSW, 2014), used a survey design to seek feedback from service providers and a cross-sectional analysis of at-risk families. The report noted that only 5 per cent of respondents were from disability services. This limits the applicability of these findings to families of children with disability. The absence of evaluation studies of prevention programs or strategies for sexual abuse of children with disability is a disturbing knowledge gap. That said, the lack of effectiveness and efficiency studies overall of child protection prevention and intervention strategies is well documented and as recently as the 2015 report on *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 (Commonwealth of Australia, 2015). This serious knowledge gap about what works for whom, to what extent and under what circumstances needs to be urgently addressed.

## 4.5 Prevention of sexual abuse of children with disability

In this section we present findings on prevention approaches using the situational prevention framework of Kaufman et al. (2012) followed by the identification of key themes relevant to the application of prevention strategies in the disability sector. Under each framework heading we first report findings from the scientific and grey literature including that sourced internationally. The findings overall consist of recommended prevention strategies and suggested program approaches. This is indicative of a literature in which there is a dearth of evidence on best practice and/or tried and tested prevention strategies.

The findings in this section from the scientific literature come from that examined for Research Question 2, the Robinson (2012) report, the Cochrane Systematic Review (Walsh et al., 2015) and the two evaluation studies of Bowman et al. (2010) and Lee and Tang (1998). The findings from the grey literature in this section come from recommendations found in reports from inquiries, practice and program approaches in Australia and three more widely referenced prevention approaches found in the international literature. For ease of presentation, the findings from the grey literature are summarised in the Appendix Table 2.

#### **4.5.1 Prevention strategies/interventions focused on the child**

Programs, interventions and educational materials need to be inclusive and tailored to the specific needs of children with disability. Several authors commented on the need to modify existing materials depending on the nature of the child's cognitive, physical and emotional abilities. The format of prevention materials as well as how these are delivered need to be accessible, understandable and available in different formats, for example in braille/large print, using pictures and graphics, and Easy English as appropriate to the child participant audience (Alriksson-Schmidt et al., 2010; Devries et al., 2014; Everett-Jones & Lollar, 2008). Ammerman et al. (1994) suggested that questioning child participants about indicators and instances of sexual abuse may have value in the detection of abuse. Specific recommendations included increasing the ability of children with disability to identify, prevent and report sexual abuse (Lee & Tang, 1998; McEachern, 2012; Reiter et al., 2007).

The grey literature is more extensive on programs and policy directives in relation to prevention and intervention strategies for sexual abuse of children with disability. Primarily these adopt 'the child as empty vessel' approach rather than viewing the child as an active agent with the capacity for learning, being aware of the possibility of sexual abuse, and the ability to change and to make choices. Initiatives and policy actions that refer specifically to children and young people with disability are scarce. Robinson (2012) noted a wide range of broad policy and practice initiatives in the National Framework for Protecting Australia's Children (COAG, 2009) from which children and young people with disability may benefit. However generalist population programs may have limited effectiveness without also targeted interventions relevant to the particular circumstances and institutional settings of children with disability.

Robinson and McGovern (2014) suggested that gathering perspectives of students with disability in relation to harm might help reduce and generate effective strategies to keep children safe. In other areas of disability research it is well accepted that involving individuals with disability and incorporating their perspectives in program design lead to greater program engagement and more effective program outcomes. As Robertson (2012) noted disability-inclusive program development is particularly critical when 'normative understandings of children, and of child abuse, exclude children with disability, or that they include them only partially, in broader initiatives about preventing abuse of children and responding when it does occur' (p 17).

In recent years a great deal of work has been conducted on sexuality with individuals with disabilities, particularly with people with intellectual/developmental disability. Initially this work derived from a risk paradigm, with programs and interventions designed to protect/prevent people with intellectual/developmental disability engaging in sexual or intimate behaviours. The focus is now on assisting people with disability to become aware of themselves as sexual beings and to experience safe and fulfilling sexual lives (Jahoda & Powell, 2014; Martinello, 2014). One evidence-informed Australian program Living safer sexual lives (Johnson et al., 2001) has been used in many programs for adults with intellectual/development disability around Australia. As yet it has not been adapted for use with children and adolescents. Two points are worthy of attention in relation to programs such as this. As the authors noted, one of the barriers to implementing sexual abuse prevention is the capacity to secure funding. Another is that those wishing to provide such programs need to ensure that practitioners are well trained and capable of providing appropriate support so that people with disability are not made more vulnerable in reliving the experiences of abuse.

Briggs and Hawkins (2005) in their New Zealand study of 116 students with an intellectual disability noted that children with learning disabilities may be viewed as targets because ‘they would be less aware of the difference between right and wrong’ (p 19). As a prevention strategy it was recommended that students be taught personal safety skills in schools and that police officers and teachers were perceived as being best suited to do this. It is noted that the results of this study related to abuse broadly and were not specifically in relation to children with disability, sexual abuse and institutional settings.

#### **4.5.1.1 Specific programs relevant to children with a disability**

Three Australian programs were located which offer the opportunity for safety conversations and consumer/client training to assist in navigating intimidating or unhelpful relationships. These training opportunities, targeting children with learning delays, also focus on the law and sexual victimisation. The first of these is the Family Planning ACT Schools disability program training package for young people and adults with intellectual disability. The second is the SoSafe! Tools and training resource delivered by Sexual Health and Family Planning (ACT), which also incorporates the use of the ‘touch triangle’ concept in terms of educating children and young people about safe touching. The last program is the Relationships and private stuff training workshop conducted by a private practitioner in New South Wales. These programs assume a certain level of communication and language capacity. We were unable to locate any programs for children with multiple disabilities or complex communication difficulties.

Information available from Commonwealth and state governments and statutory agencies that was located included policy directives, frameworks and guidance for practitioners. One example is the material available from the Department for Education and Child Protection South Australia (2012). This material is the most comprehensive in Australia to present information on regulatory background checks and guidelines for child-safe organisations as well as a user-friendly parent booklet

that includes a practical checklist for parents (Protecting Children and Young People with Disability. A Booklet for Parents, Department for Education and Child Protection South Australia, 2013). Materials such as these or in other states such as Western Australia from the Children and Young People Commissioner (2016) offer a coordinated approach for children and young people, their family and child safe organisations (<https://www.ccyp.wa.gov.au/our-work/resources/child-safe-organisations/>).

In contrast, specific fact sheets may be based on legislated schemes such as the NSW Working with Children Check (<https://www.kidsguardian.nsw.gov.au/working-with-children/working-with-children-check>) or informed by evidence on the particular vulnerabilities of specific groups of children. These approaches typically focus on engaging staff at all levels in provider organisations, with specific responsibilities set out for personnel at each level in the organisation. There are also instances where statutory agencies work directly with and respond to people with disability, for example, the NSW Ombudsman (<https://www.ombo.nsw.gov.au/>). This office provides information and workshops directly to people with a disability to ensure consumers understand their rights and the complaints procedures available to them. The Office of the Public Advocate Community Visitors Scheme in Victoria offers an extension of this approach (<http://www.publicadvocate.vic.gov.au/our-services/community-visitors>).

The application of these focused initiatives for staff and other organisation personnel, and coordinated approaches to engage with children, their families and organisations in both specialist and mainstream settings is yet to happen in Australia. The strategic implementation of such systematic approaches should be subject to evidence-informed evaluation to understand their effectiveness and efficiency in preventing sexual abuse of children with disability.

#### **4.5.2 Family prevention strategies**

Mueller-Johnston et al. (2014), McEachern (2012), Miller (1993) Turner et al. (2011) and Verdugo et al. (1995) discussed the importance of child–caregiver relationships in ensuring children with disability are aware, safe and able to communicate any instances of maltreatment. These authors suggested the introduction of programs that improve child–caregiver communication skills, increase the quality of the child–caregiver bond and build trusting, positive relationships. This could be done by using strategies to enhance communication between families and children about children’s rights, procedures for reporting abuse, and how to locate a safe place.

Information in the grey literature for families and carers focuses primarily on the understanding of risk factors, despite the evidence on risk factors being ambiguous and of an international nature, as discussed in section 3. Family Planning NSW and Shine SA (formerly Family Planning South Australia) provide online resources which use prevention language (see Appendix Table 2).

#### **4.5.2.1 Specific programs relevant to carers and family members**

Programs that focus more specifically on providing information to parents of children with a disability were identified through an analysis of grey literature. An example of this is the South Australian Protecting children and young people with disability. A Booklet for parents and carers available at [http://www.macswd.sa.gov.au/files/links/Protecting\\_children\\_and\\_yo.pdf](http://www.macswd.sa.gov.au/files/links/Protecting_children_and_yo.pdf) and its companion document, A guide to protecting children and young people with disability. For parents and carers available at <http://www.secasa.com.au/assets/Documents/a-guide-to-protecting-children-and-young-people-with-disability-and-preventing-sexual-abuse.pdf>. This type of approach aims to instruct parents how to keep their child safe by upskilling children about protective behaviours and understanding sexualised behaviours. This approach also aims to teach parents and caregivers the skills to identify indicators and signs of sexual abuse.

There is no available evidence on whether this type of ‘awareness-raising’ information is effective. Similarly it is not certain whether government materials which rely on parents to become acquainted with agency policies and procedures are effective. This latter approach relies heavily on ‘information savvy’ parents. These types of materials do not address the needs of parents who may need targeted interventions as well as population prevention approaches.

#### **4.5.3 Prevention strategies for staff/managers of organisations**

The scientific literature emphasises the importance of a whole of organisation approach. This means all staff in institutional settings and all workers associated with the institution. This includes casual staff, outdoor staff and others not directly responsible for children such as the staff in a school canteen or tuckshop.

Specifically, Bowman et al. (2010), Devries et al. (2014) and Sullivan et al. (2000) recommended the need for training of staff in institutional settings to recognise signs of abuse and also to respond to these signs both by reporting appropriately and putting practices in place to safeguard the child. Alriksson-Schmidt et al. (2010), Bowman et al. (2010) and Devries et al. (2014) focused attention on the need to increase staff knowledge and the capacity to respond appropriately. These authors specifically recommended education programs to cover factors that increase the risk of abuse occurring and protective factors and strategies to minimise occurrence.

Less emphasis was placed on governance procedures in the scientific literature although this is a frequent focus in the Australian grey literature. The Australian grey literature emphasises the importance of prevention strategies targeting staff of disability-specific organisations. Training and staff screening are frequently mentioned. Table 2 in the Appendix shows that policy development and program implementation are current key strategies used to target awareness of staff or organisational level. Kaufman and Erooga (2016) noted that ‘there has been a call for prevention planning that is more reflective of offenders’ specific patterns of child

sexual abuse perpetration' (p 91). These authors went on to state that training requirements, early detection of staff behaviours of concern, facilitation of staff reporting other staff, and the need to engage families, carers and other stakeholders are all part of the prevention 'solution'. Attention to all these factors is not evident in the Australian grey literature.

In line with the more recent recognition of whole of organisation approaches to keeping children safe, a number of Australian agencies have produced guidelines on child safe organisations. One example is the Victorian Children's Commission for Young People Tip sheet: child safe organisations (n.d. available at <http://www.cryp.vic.gov.au/downloads/tipsheets/tipsheet-safety-children-disability.pdf>). This is based on the understanding that children and young people due to their developmental age and stage and being in a dependent relationship with adults have limited capacity to identify and report concerns. This places the responsibility squarely on the staff and organisation to create a child-safe culture where children are safe and empowered to speak out and to seek support.

From an organisational culture perspective the grey literature highlights the need to explore the vulnerability of children as being more than 'the disability'. This is encouraging and in line with the change in perspective which regards individuals with disability as people first, disability second (CRPD and the national disability reform agenda). The National Disability Strategy (Commonwealth of Australia 2011a) is clear on this point. Under the second area of policy action Rights protection, justice and legislation, Policy Direction 4 states that 'people with disability to be safe from violence, exploitation and neglect' (p 38).

In the grey literature it is anticipated that changes in staff culture and the way in which supports are provided along with a deeper understanding of the vulnerabilities of disability may heighten awareness of and response to people with disability, their supporters, support providers and the broader community in relation to abuse, neglect and exploitation. There are also concerns noted that over-emphasis on child-safe organisations may overlook or negate critical awareness and knowledge about potential or actual perpetrators of child sexual abuse. In other words, that organisational practices may tend to de-emphasise actions taken by individuals which harm children, including sexual abuse.

Quadara, Higgins and Siegal (2015), writing about Australian child sexual abuse and policy and practice challenges more generally, noted that prevention approaches can only be effective when the higher level policy directives intersect with initiatives surrounding protecting children from harm. The potential offered by the National Disability Strategy 2010–2020 (2011) and National Framework for Protecting Australia's Children (COAG 2009) and subsequent implementation plans is yet to be realised in evidence-informed and evidence-generating prevention approaches in Australia.



#### 4.5.4 Prevention strategies with an organisation / community focus

The remaining level in the Kaufman et al. (2012) situational prevention framework speaks to an integrated organisational, agency and community prevention approach. It is through this lens that the literature on prevention strategies at an organisational level is explored.

In the scientific literature there is concern for implementation, monitoring and evaluation frameworks at government level to ensure all institutions comply with disability legislation. In the US for example, this is the Americans with Disabilities Act, 1990) and the Education for All Handicapped Children Act, 1975). Complying with legislative and regulatory requirements is critical to ensure safe environments for children with disability. It is also critical as McEachern (2012) noted to ensure the relevant agencies such as law enforcement and child protection systematically collect and report data on sexual assaults and abuse. This is needed to ensure an accurate account of the frequency and extent of sexual abuse of children with disability, where this is most likely to occur, and factors which militate against sexual abuse of children with disability occurring in institutional contexts.

Reiter et al. (2007), Sullivan and Knutson (2000) and Sullivan et al. (2000) recommended good communication systems between sectors and accurate recordkeeping with reliable data are critical to understanding the presence and extent of sexual abuse of children with disability. Further, in our view, when this data can be linked across sectors and aggregated across institutional settings such as education, child welfare and law enforcement there is a greater possibility of understanding the necessary and sufficient elements of child safe institutional settings. For example, ensuring there are effective referral mechanisms and appropriate counselling services for all children who are sexually abused, including children with various disabilities, and in ways which are universally accessible for these children (e.g. Aliksson-Schmidt et al., 2010).

Skarbek et al. (2009) in a study of sexual abuse prevention for children with disability explored prevention and intervention programs that rely on Bronfenbrenner's ecological model. The authors suggested prevention at three levels – primary, secondary and tertiary. At each level prevention strategies need to be identified relevant to whether abuse is known to occur or has not yet occurred. For prevention at the primary level (where abuse has not yet occurred) it is suggested the focus should be on communication and relationships between the child and carer, staff recognition of relevant policies and procedures, and organisation understanding about how to protect children. The secondary and tertiary levels the authors suggested relate to circumstances where abuse is known to have occurred and relies on engagement with mandatory reporting guidelines, multidisciplinary support services enacted to assist the child, and understanding of the impact of abuse on behaviour.

In addition to the scientific literature, our analysis of grey literature addressed the strategies that could be used by children and their carers and by staff within organisations. The literature identifies briefly the role of bystanders in the prevention

of sexual abuse for children with disability. Robinson (2014) for example noted that 'at the community level, engaging bystanders to take action against abuse and neglect of children and young people with disability is a way to broaden the base of support in both preventing harm and in ensuring when it happens, it is effectively responded to' (p 27). A focus on the role of individuals outside the child, family or staff member is thought to assist the development of community-based prevention strategies. Open and transparent information sharing relies on organisations being committed to and developing an appropriate culture to achieve this or being mandated to do so by legislation or governance mechanisms. It also relies on effective internal mechanisms to ensure data is reliably recorded and accessible and able to be transmitted in a timely, reliable and confidential manner.

## 4.6 Two contributions from the international grey literature

Two international reports on effective prevention strategies were analysed to supplement the scarcity of Australian grey literature. These come from Stop it now! (US and UK) and the National Society for the Prevention of Cruelty to Children (UK) which also incorporates mention of the Eradicating child sexual abuse (ESCA) database from the Lucy Faithfull Foundation (UK).

The first approach, a guide titled *Family safety planning for parents of children with disabilities* published by Stop it Now! (US, UK and Ireland based organisation), is designed for families and carers to enhance opportunities to keep children with disability 'safe' (<http://www.stopitnow.org/ohc-content/tip-sheet-family-safety-planning-for-parents-of-children-with-disabilities>). The guide explores issues of both sexuality and sexual safety by asking families to understand their child's unique vulnerabilities rather than relying on the singular concept of 'disability' as predictive of risk. The guide encourages families to establish guidelines for care of their child by imposing limits, such as the degree of assistance their child requires with personal care. This guide addresses expectations about sexual vulnerability through the identification of safe people in the lives of the child and knowledge about local statutory resources if concerns arise.

The second approach comes from the National Society for the Prevention of Cruelty to Children (UK). Its most recent publication, *Preventing child sexual abuse. Towards a national strategy for England* (Brown & Saied-Tessier 2015), investigated specific strategies for children with disability to use in preventing abuse. They reported that although information is available for children about staying safe, this information has to be made accessible particularly for children with limited communication. This report also discussed the Eradicating Child Sexual Abuse (ECSA) database. This is an international repository of prevention approaches currently managed by the Lucy Faithfull Foundation (UK). This foundation is a registered charity that seeks to assist in the prevention of sexual offences as well as studies the effects of prevention strategies. It is currently completing the three-year ECSA project funded by Oak Foundation Switzerland.

The database, currently seeking submissions, cites primary, secondary and tertiary factors that impact on the number of children at risk, including children with disability, and the potential for prevention strategies to have a targeted approach. A 2013 review of the ECSA is available at

[http://www.lucyfaithfull.org.uk/ecsa\\_eradicating\\_child\\_sexual\\_abuse.htm](http://www.lucyfaithfull.org.uk/ecsa_eradicating_child_sexual_abuse.htm). At the time of this review there were 170 self-report submissions from agencies across the world on prevention campaigns relating to sexual abuse and children. A preliminary analysis of the database found that 'whilst a great deal can be done to prevent the sexual abuse of children, current approaches are often inadequate in scope, poorly targeted and lacking evaluation' (Lucy Faithfull Foundation, 2013).

The ECSA-Prevention Framework uses a four by three matrix for prevention (see <http://www.lucyfaithfull.org.uk/files/ECSA%20Framework.pdf>). The first part of the matrix utilises a public health model of primary prevention (preventing child sexual abuse before it would otherwise occur); secondary prevention (reducing the risk of child sexual abuse in 'at risk' groups); and tertiary prevention (preventing further child sexual abuse offences by known child sexual abuse offenders and preventing revictimisation of known victims). The second part of the matrix identifies four distinct sets of prevention targets. These are offenders and potential offenders; children and young people (victims); families and communities; and situations (for example institutional contexts). The Annual Report of the Lucy Faithfull Foundation identifies that: 'The ultimate goal is the provision of a toolkit that will assist a nation, area or region, anywhere in the world, to develop a considered and credible strategy for the prevention of child sexual abuse within that nation, area or region' (2015, p 23).

The ECSA-Prevention Framework reports that this will occur through the collection of information from service providers about the prevention programs they facilitate and data regarding their efficacy. The project is due for completion in 2016, with analysis of the toolkit to be shared via the International Society for the Prevention of Child Abuse and Neglect (ISPCAN). Finalisation of this project and sharing of findings will, we anticipate, offer the evidence-based information that is currently sorely lacking to inform Australian policy directives on creating child safe organisations and keeping children with disability safe.

# SECTION 5 Synopsis and key messages

In this concluding section we offer a synopsis and key messages derived from the historical understandings and changes in discourse about disability in Australia over time and analysis of the international scientific and Australian grey literature on prevalence and risk of sexual abuse against children with disability. This synopsis is contextualised by our experience and expertise derived from research, practice, policy debate and submissions and inquiries over more than four decades in matters related to families and children with disabilities in the Australian context.

## 5.1 Disability reform in Australia

### 5.1.1 Exclusion and mental treatment

Prior to the 1970s and despite the community perception to the contrary, most children and adults with disability lived at home with their families. In line with community thinking, families assumed responsibility for their children with disability, managing as best they could with extended family and charitable support. Their children were rarely seen in public; in many cases they were kept hidden from neighbours and the wider community.

When families were unable or unwilling to care for their child with a disability, they were placed away from public scrutiny in government 'mental' institutions or charitable disability hospitals. This became 'home' for the rest of their lives. Government inquiries over decades (Swain, 2014) record multiple instances of neglect, with barely adequate basic care and limited day activities, and instances of physical, emotional and sexual maltreatment often meted out as 'punishment' for 'bad' behaviour.

### 5.1.2 First wave of reform – recognising the rights of people with disability

The first wave of reform began in Australia in the late 1970s following international momentum to secure human rights for all, including people with disability. For those living in 'care' little changed until the 1980s despite the 'outing' of abuse and sub-standard living conditions in institutional contexts by national inquiries. A driver of change came with the heavy promotion of normalisation in Australia. The normalisation principle states that people with disability should be assisted to establish patterns of life as close as possible to those of society more generally. This was clearly impossible within the closed walls of segregated institutions or children in family homes kept out of sight of the community's gaze.

Reform began first in the education sector. Commonwealth initiatives, for the first time, focused on providing funding to educate children with disability including those with more severe and profound disabilities. International developments in particular the US 1975 Education for All Handicapped Children Act fuelled optimism and action across Australia to develop appropriate educational opportunities for children with disability.

Reform began later, proceeded more slowly, and is still continuing today to move adults and children with disability out of institutions and into the community. The deinstitutionalisation movement did not begin to gather momentum in Australia until the late 1980s. This was despite the landmark *New Directions* report of 1985 in which, for the first time in Australia, people with disability were acknowledged as more than sick and more than dependent. Senator Don Grimes makes this plain - 'People with disability ..... have made it clear that they want to be treated as people first – people whose abilities matter more than their disability' (*New Directions*, 1985 Foreword, p iii).

Legislative reform followed based on human rights and active citizenship principles for people with disability. Commonwealth then state and territory legislation set the tone: people with disability were people first and entitled to a respected place in society, support and services, due process and protection from harm.

### **5.1.3 Second wave of reform – towards realising the rights of people with disability**

Reform faltered in the following decades. International human rights treaties such as the UN Convention on the Rights of the Child had little impact for children with disability in Australia. By the 2000s however people with disability and their families and carers were no longer willing to stay quiet and 'grateful'. The impetus for the second wave of reform came from the United Nations Convention of the Rights of Persons with Disabilities (2006). No longer could governments and to a lesser extent the public ignore the voices of people with disabilities requesting their rightful place in society.

So began the first decade – 2006-2016 – of the national disability reform agenda. The National Disability Strategy 2010–2020 came just over 20 years after the Disability Services Act (C) 1986. The fundamental purpose of the strategy is to include Australians with disability as full and equal citizens in Australia society. A national disability research agenda was developed to focus research on the actions foreshadowed in the disability strategy. The reform agenda dictates that people with disability participate in the mainstream of society – in health, education, transport, housing and so on – and access specialist support and services only when required. The National Disability Insurance Scheme sets out to bring this to fruition.

To achieve the promise of mainstreaming requires inclusive and accessible communities. The human rights, social and economic imperatives of the National Disability Strategy are now well embedded in Australian legislation, governance mechanisms and policy directives. Nevertheless, to achieve inclusive and accessible

communities requires a paradigm shift in community attitudes. Communities and institutional contexts can only become inclusive and accessible when they too take on board that people with disability are citizens first and foremost, and entitled to a respected place in society, due process and protection from harm.

## 5.2 Children with disability and their vulnerability to harm

The national disability reform agenda is not enough. As we have demonstrated, this reform agenda is mostly silent on children with disability. Policy frameworks and mechanisms focus attention on supporting their families and appropriately so. This comes at a price however. Children with disability are positioned as dependent, passive and under the care of their parents. When children with disability are stereotyped in this way they are at heightened vulnerability to abuse, being segregated, overlooked and not heard. In our view: as in the past, now in the present. Australia has a long history of exclusion of children with disability from society either in institutions or 'protected' within the family home. The perspectives of children with disability – their voices – are missing from the disability reform agenda.

### 5.2.1 Prevalence and risk of sexual abuse for children with disability

There is no Australian data on prevalence and risk of sexual abuse for children with disability. This is a major failing. In its absence advocates and researchers have turned to the international literature on children with disability. They have also drawn conclusions from the more substantive literature on sexual abuse of adults with disability.

The most reliable prevalence figure comes from an international systematic review and meta-analysis of violence toward children with disability (Jones et al. 2012). The authors reported a pooled prevalence figure of 13.7 per cent for sexual abuse based on 15 studies (none from Australia). Because of the extreme range (1 per cent–40 per cent) they also report a fixed-estimate prevalence rate which is lower, at 8.9 per cent. Together these figures suggest that between 9 and 14 children in every 100 children with disability are likely to experience sexual abuse.

There are obvious drawbacks in rigidly asserting one figure as the 'true' prevalence. Nevertheless, the international figures suggest heightened vulnerability to sexual abuse and they align with other vulnerabilities that are experienced by children with disability. These include discrimination, social exclusion, poorer development and lower wellbeing.

A single prevalence figure however does not shine light on the critical policy and practice questions of which children are likely to be subject to abuse, to what extent and under what circumstances. There are pointers that children with intellectual



disability and psychological disorders are at greater risk of sexual abuse. The jury is out on whether gender or age influence risk of sexual abuse. Critically there is no robust population evidence on the impact of particular institutional contexts on prevalence and risk of sexual abuse for children with disability. There is some Australian evidence that children with disability are proportionately over-represented in reportable incidents of all types emanating from the out-of-home care and education sectors.

### **5.2.2 Prevention approaches**

One could expect that heightened vulnerability to harm would lead to increased efforts to develop evidence-informed approaches to prevent sexual abuse. The opposite is the case. The physical exclusion of children with disability plays out in their virtual absence from national frameworks and implementation plans to protect all Australia's children. As well, and again despite heightened risk, there is no evidence base in Australia on effective and cost-efficient prevention strategies to reduce sexual abuse of children with disability. This is another major failing.

In the absence of an evidence base, researchers and advocates have put forward recommendations for prevention approaches to be trialled and tested. Recommendations focus on children, families, on organisational mechanisms and cultures, and the wider community. The primary concern is to include children with disability in all child-focused prevention approaches, rather than exclude these children and young people from learning about sexual abuse, when they more than others are likely to become sexual abuse victims.

The principle of ensuring the voices of children are present in matters affecting their lives is now well accepted. This principle needs to be extended to children with disability, and particularly as active participants in developing protective behaviours. To be effective in meeting the needs of children with disability, adults – policy makers, families, practitioners – need to be prepared to see the world through the eyes of these children and young people. This is critically important given that exclusionary practices based on stereotyping children with disabilities as less capable, more dependent and less sexual than their peers lead to 'over protection' and greater vulnerability. When relevant knowledge is available and skills taught, these build capacity, resilience and protective behaviours.

The over-representation of children with disability in reportable conduct matters implies that attention needs to be focused on 'closed contexts' that are high risk settings. Disability-specific settings such as respite care, school transport and personal care services feature one-on-one interactions between adults and children. This is particularly relevant to quality and safeguarding in the changing disability services context in Australia. The NDIS is predicated on a market expansion of disability specialist supports and services. This raises questions of provider 'safety' at all levels: organisational, staff and individual providers. Effective governance and monitoring mechanisms need to ensure best practice, standards compliance and accessible complaint processes.



Working with children checks already exist in Australia; a vulnerable persons' check is one possible solution to monitoring all individuals working with persons with disability including children. National disability service standards have existed in Australia for some time. However, these standards remain adult focused. They do not address child safe organisations, support services or independent providers. The disability standards also focus on disability-specific contexts. Children with disability no longer find themselves in disability specific contexts only: their everyday lives are also spent in mainstream settings in education, recreation and health. Mainstream institutional contexts also need to be safe for children with disability. Inclusive approaches require a comprehensive national (or nationally consistent) system to ensure and monitor child safe organisations in specialist and mainstream settings.

National regulation while necessary is unlikely to be sufficient. Building, maintaining and sustaining child safe organisations is the responsibility of management accountable to an organisation's governing body. This requires leadership, policies and practices, and an organisational culture in which children always come first. Disability-specific organisations may not be particularly familiar with or have strong networks within the mainstream child sector and the leadership and practices required to build, maintain and sustain a child safe organisation.

Specialist disability organisations and their peak bodies could benefit from engaging in 'communities of practice', which are becoming a regular feature across child, education, health and welfare sectors. Simply put, communities of practice are groups of people who come together – face to face or virtually – to share knowledge and experience to forge better practice in their respective fields of endeavour. How communities of practice are organised and supported varies widely. That said, these typically include diverse, open and transparent communication channels to share professional wisdom, and working to create resources to assist organisations, families and communities to respond better within their field of endeavour. Developing a community of practice in Australia relevant to the particular needs and contexts of children with disability in disability-specific and mainstream service settings would be a major step forward.

### **5.2.1.1 Children with disability as a special group**

The current approach in Australia tends to focus on children with disability as a special group. In our view, there are distinct dangers in doing so. The most obvious is that responsibility for special groups is thought to reside 'outside' the mainstream. The converse is that the mainstream is 'relieved' of their responsibilities for children with disability. This is contrary to Australia's obligations under CROC and CRPD. Child safe organisations must be child safe for all children. This means that in child safe organisations due diligence must be paid to ensuring any particularities relevant to children with disability are understood and responded to using evidence-informed strategies, practices and behaviours.

This discussion paper highlights the role of services and various communities in responding to and supporting children and young people living with a disability. There is considerable professional expertise in the Australian disability community that has begun to explore primary prevention strategies. Finding ways to strategically

enhance this community of practice by bringing together the resources of service providers, families, communities and individuals with lived experience may enhance the development of what a child safe organisation requires for all children, not only those living with disability.

In our view, it is not enough to include disability only as a cross-cutting theme for child safe organisations. This is because community attitudes and the ways in which children with disability have been treated in the past places them at heightened vulnerability to violence including sexual abuse. Community attitudes play out in institutional contexts. These attitudes have to be changed. This requires a direct approach. For an organisation to be safe for children with disability a population-based approach will not be enough. The past tells us that children with disability would continue to be ignored. Targeted interventions will also be needed to reduce the heightened risk of sexual abuse for children with disability. Disability and mainstream organisations must be child safe for all children and demonstrate their competence to remain so over time.

### 5.3 New directions for children with disability

There is tragic irony in understanding that children with disability are at a heightened risk of sexual abuse related to child characteristics, settings and organisational factors, yet national legislation and policy frameworks are virtually silent on this point. Attitudes toward disability, segregation and institutionalisation, treating children with disability as a small and special group, or assuming that the community takes care of its most vulnerable should not continue as excuses for inaction.

This discussion paper points to the exclusion of children with disability in many areas of life which affect them most deeply, including knowledge about sexual abuse in institutional contexts. The Audit of Disability Research in Australia (Centre for Disability Research and Policy 2014) reported that research on inclusion and participation of children and young people with disability in everyday life was significantly under-represented in the Australian disability evidence base.

To inform implementation of child safe organisations in Australia researchers need to address the following question set out at the beginning of this Discussion Paper. That is, which Australian children with disability are more likely to experience sexual abuse, to what extent, and under what circumstances. This implies researchers investing time and research agencies investing funds to: (i) address the particular circumstances of heightened risk of sexual abuse for children with disability; and (ii) to address children with disability as an integral part of the reform agenda on bringing people with disability into everyday institutions in the community.

The Audit recommended expanded research efforts using administrative data sets such as the National Child Protection Minimum Data Set (AIHW 2014). One way to do this is to make it easier for disability researchers and policy makers to use registries and routine surveys and data sets. It is a truism that only that which is

measured counts. The over-representation of children with disability in care and protection proceedings and out-of-home care is on the public record. Routine and reliable identification of disability in administrative data sets will go a long way toward better understanding the specificities (as above) of sexual abuse of children with disability in institutional contexts in Australia. There is in principle agreement to do so across all jurisdictions but this has not yet been implemented. As the recent World Health Organisation (2015) publication Toolkit on mapping legal, health and social services responses to child maltreatment reports 'Recently, Australia advanced from provincial data sets on child maltreatment incidence to a national minimum data set of child protection' (2015, p 7). Footnote 10 notes that 'However, as two of the eight jurisdictions still chose to report aggregate data due to competing priorities, the picture is not complete' (p 7). This means that the Australian Institute of Health and Welfare responsible for reporting on the Child Protection National Minimum Data Set is not yet able to report disability data (AIHW, 2014).

Further, the Audit also commented on the need to expand Australian longitudinal child cohort studies. This includes over-sampling of children with disability to ensure adequate sample sizes to understand the potential drivers (social, economic, cultural, impairment-related) of maltreatment of children with disability. One of the findings of the Audit in relation to the disability evidence base in Australia is the higher proportion of study designs which explore or investigate attitudes, knowledge or perspectives. This means:

These studies essentially describe the 'problem'. While an important contribution, descriptive research cannot produce evidence based solutions (although it may propose solutions to be tested in the future). There was much less research using study designs which test interventions or solutions or evaluate policy initiatives. In other words, study designs that allow us to know what works, and ideally, for whom and under what conditions. Research that can determine what works and in which settings is urgently needed. For example, the disability reform agenda aims to ensure people with disability can access and use mainstream activities and services to participate fully in all aspects of society. Research on how to achieve accessible and participatory mainstream services, and at scale and across all sectors is currently missing from the disability research base in Australia ... It would be misleading to only focus on the situation of people with disability. Without comparison within and between groups of people, we cannot know whether the policy initiatives of the disability reform agenda are working, and in the desired direction, and for whom. (Centre for Disability Research and Policy, 2014, pp 8-9)

This statement applies equally to children with disability. Ensuring that population data and administrative data sets include and are relevant to children with disability is critical to be able to compare their circumstances alongside that of their non-disabled peers. We repeat: it would be misleading to focus only on the situation of children with disability. Without comparison within and between groups of children we cannot know whether the policy initiatives of the reform agendas on disability and on protecting children are working, and in the desired direction, and for whom.

# Appendix

**Table 1 Characteristics of the two interventions on sexual abuse of children with disabilities**

Study	Bowman et al. 2010	Lee & Tang 1998
Country	USA	Hong Kong
Study design	Cohort: pre and post, no control group	RCT <sup>#</sup>
<b>Participants</b>		
Gender	73.2% female	100% female
Age	Mean = 30.1years	11-17yrs at special school for children with mental retardation
Intervention Group	124 service providers	38
Control Group	NA*	34
<b>Disability type</b>	Developmental disabilities	Mild mental retardation
<b>Intervention</b>	Training program for service providers (4hr workshop)	2 x 45mins sessions with children
<b>Outcome Measures</b>	Pre and Post: Sexual Abuse Attitudes & Knowledge Questionnaire (SAAKQ) Global Perceptions Scale (GPS) – assesses general attitudes about people with disabilities	Pre, post, 2mth follow-up. <i>Intervention Group:</i> ‘What If’ Situation Test <sup>+</sup> – measures ability to differentiate appropriate from inappropriate sexual advances and knowledge about self-protection skills in response to hypothetical abusive situations Personal Safety Questionnaire <sup>+</sup> – assesses sexual abuse knowledge Fear Assessment Scale <sup>^</sup> – assesses fear of various objects, people and situations <i>Control Group:</i> Attention Control Program <sup>§</sup> – covers various safety skills unrelated to sexual abuse (for

		example, car safety, stranger safety, playground safety)
<b>Results</b>	<p>57% completed pre- and post-test:</p> <p>SAAKQ Knowledge scale increase 34 to 42.3/70, p&lt;0.001</p> <p>SAAKQ Attitude scale increase 3.7 to 3.9, p&lt;0.001</p> <p>No significant change in GPS</p>	<p>Improvement in knowledge about sexual abuse and self-protection and maintained for 2mth</p> <p>Improved recognition of appropriate touch requests dissipated with time</p> <p>Intervention group showed less fear after 2mths – showing they became better equipped to recognise appropriate and inappropriate touch</p>
<b>Recommendations</b>	<p>More intensive training and follow up (due to small changes)</p> <p>Agencies provide sexual abuse training to developmental disability service provider</p>	<p>Booster sessions and longer program duration to show better retention of learned material</p> <p>Include ratings of parents and teachers on instruments</p>
<b>Limitations</b>	<p>Participants (primarily young women) may not be representative of all service providers</p> <p>Low post participation rate</p> <p>Attitudes and global perceptions may be difficult to see change after only 4 hours</p>	<p>Self-report (question whether the verbal descriptions of skills can translate into actual self-protection behaviour in the natural environment</p> <p>Findings cannot be generalised to other disabilities</p>

\*NA – not applicable; #randomised control trial; \*Wurtele, 1990; ^Wurtele & Miller-Perrin, 1997; \$Wurtele et al., 1992

**Table 2 Prevention programs, policy frameworks and Australian initiatives targeting prevention of child sexual abuse in institutional settings including children and young people with disability**

Topic	Author / Program implementer / available at	Agency type	Program / Policy detail
<b>Child Focused</b>			
<i>'Relationship and Private Stuff'</i> Workshops to support people with intellectual disability	Private practitioner, NSW <a href="http://www.relationshipsandprivatestuff.com">http://www.relationshipsandprivatestuff.com</a>	Private enterprise, disability-specific	Sexual awareness and sexual safety for young people with disability
<i>Schools disability program</i>	Sexual Health and Family Planning ACT <a href="http://www.shfpact.org.au/community-health-promotion/schools-disability-program">http://www.shfpact.org.au/community-health-promotion/schools-disability-program</a>	State-funded, Health	Social safety, sexual and reproductive health needs (including the law regarding harassment and assault)
<i>Feel Safe CD (2015)</i>	True relationships and reproductive health (Formally Family Planning Qld) <a href="http://www.true.org.au/Resources/shop#!/Feel-safe-CD/p/57318487/category=18053014&amp;forcescroll=true">http://www.true.org.au/Resources/shop#!/Feel-safe-CD/p/57318487/category=18053014&amp;forcescroll=true</a>	State-funded, Health	Self-protection resource for young people 12-16 years with a learning disability
<i>I have a right to be safe (2015)</i>	True relationships and reproductive health (formerly Family Planning Qld)	State-funded, Health	Self-protection skills resource of flip charts and brochures for children 5-10 years

	<a href="http://www.true.org.au/Resources/shop#!/I-have-the-right-to-be-safe-flip-chart-and-brochures/p/57318730">http://www.true.org.au/Resources/shop#!/I-have-the-right-to-be-safe-flip-chart-and-brochures/p/57318730</a>		with limited learning skills
Reportable incidents scheme for people with a disability in supported accommodation (2014)	Ombudsman NSW <a href="https://www.ombo.nsw.gov.au/what-we-do/our-work/community-and-disability-services/part-3c-reportable-incidents">https://www.ombo.nsw.gov.au/what-we-do/our-work/community-and-disability-services/part-3c-reportable-incidents</a>	Statutory agency, NSW	Online and telephone complaints division established to respond to employee-client and client-client abuse and maltreatment concerns
<b>Family</b>			
Parent forum for parents/carers of people with intellectual disability	Family planning NSW <a href="http://www.fpnsw.org.au/335019_54.html">http://www.fpnsw.org.au/335019_54.html</a>	State-funded, Health	Access to resources and sharing of information relating to decision making and safety in relation to sexuality
<i>Sexuality and Disability Links – online resource for consumers, parents and carers to explore resources freely available in Australia, UK, Canada (2015)</i>	Shine SA (previously Family Planning of South Australia) <a href="http://www.shinesa.org.au/media/2015/05/Sexuality-and-Disability-Links.pdf">http://www.shinesa.org.au/media/2015/05/Sexuality-and-Disability-Links.pdf</a>	State-funded, Health	Resource kit for individuals and carers (including service providers) to seek out resources relating to sexuality and sexual safety  Limited resources for young people with disability including link to SoSAFE! training program



<b>Staff</b>			
NSW Ombudsman workshops with disability staff on client-safe environments	Ombudsman NSW <a href="https://www.ombo.nsw.gov.au/training-workshops-and-events/our-workshops/investigation-training/handling-serious-incidents-in-the-disability-sector">https://www.ombo.nsw.gov.au/training-workshops-and-events/our-workshops/investigation-training/handling-serious-incidents-in-the-disability-sector</a>	Statutory agency, NSW	Organisation workshops with focus on responding to serious incidents of abuse and allegations where there is a criminal element
Commitment to inter-jurisdictional exchange of information about people working with children	Recommendation from Commonwealth of Australia (2011)	Commonwealth directive to statutory agencies	Policy initiative to enable enhanced sharing of knowledge
<i>Zero Tolerance Framework</i>	National Disability Services in partnership with the disability sector <a href="https://www.nds.org.au/resources/zero-tolerance">https://www.nds.org.au/resources/zero-tolerance</a>	Peak body for disability services across Australia	Framework to assist disability services to implement practices that safeguard the people they support in relation to abuse and exploitation
Enhanced sharing of information regarding working with vulnerable individuals	NDIA trial roll-out (ACT) <a href="http://www.ndis.gov.au/sites/default/files/documents/quality_assurance_safeguards_working_arrangements_australian_capital_territory.pdf">http://www.ndis.gov.au/sites/default/files/documents/quality_assurance_safeguards_working_arrangements_australian_capital_territory.pdf</a>	Statutory agency, Commonwealth	To identify patterns of behaviour that may not necessarily be reflected in traditional police checks

Broad application of duty of care guidelines in the issuing of licenses for provision of services and in funding agreements	Commission for Children and Young People, Victoria <a href="http://www.cryp.vic.gov.au/childsafetycommissioner/downloads/childsafesched01.pdf">http://www.cryp.vic.gov.au/childsafetycommissioner/downloads/childsafesched01.pdf</a>	Statutory agency, Victoria	Enhanced policy directive that seeks to identify and implement structures specific to child safe organisations
Enhanced recruitment and selection processes with explicit statements of commitment to child safety in all advertising	Commission for Children and Young People, Victoria <a href="http://www.cryp.vic.gov.au/childsafetycommissioner/downloads/childsafesched01.pdf">http://www.cryp.vic.gov.au/childsafetycommissioner/downloads/childsafesched01.pdf</a>	Statutory agency, Victoria	Enhanced policy directive that seeks to identify and implement structures specific to child safe organisations
<b>Organisation / System</b>			
Australian jurisdictions work toward developing a comprehensive national data collection framework by 2022	National plan to reduce violence against women and their children, 2010-2022, Council of Australian Governments (2011)  See also: <a href="http://www.decd.sa.gov.au/docs/documents/1/Schdl3GuideInfoShrgJuris.pdf">http://www.decd.sa.gov.au/docs/documents/1/Schdl3GuideInfoShrgJuris.pdf</a>	Council of Australian Governments	Data collection relating to the protection of children including those with disability
Technology solutions to streamline and simplify notification process for complaints relating to disability services	Ombudsman NSW <a href="https://www.ombo.nsw.gov.au/data/assets/pdf_file/0008/23876/NSW-Ombudsman-submission-to-Federal-Senate-">https://www.ombo.nsw.gov.au/data/assets/pdf_file/0008/23876/NSW-Ombudsman-submission-to-Federal-Senate-</a>	Statutory agency, NSW	To assist the electronic lodgment of complaints to ensure that concerns can be raised quickly and with a notification trail

	<a href="#">inquiry-into-abuse-and-neglect-of-people-with-disability-April-2015_web.pdf</a>		
Identification of joint clients between Community Services NSW and Department of Ageing Disability and Home Care, NSW	Family and Community Services <a href="http://www.community.nsw.gov.au/data/assets/pdf_file/0004/319918/joint_practice_guidelines_cs_adhc.pdf">http://www.community.nsw.gov.au/data/assets/pdf_file/0004/319918/joint_practice_guidelines_cs_adhc.pdf</a>	State department, NSW	Streamlining of information to ensure children and young people with disability and their needs remain at the forefront of intervention
Development of a virtual centre for the prevention of violence against women and children with disabilities	Stop the violence, UNSW in consultation with peak disability agencies <a href="http://wwda.org.au/wp-content/uploads/2013/12/STV_Outcomes_Report.pdf">http://wwda.org.au/wp-content/uploads/2013/12/STV_Outcomes_Report.pdf</a>	Disability Services	The <i>Virtual Centre</i> would foster and support evidence-based approaches to more efficiently and effectively design, implement, monitor and evaluate initiatives to prevent and respond to violence against women and girls with disabilities (p 19)
12 standards for a child-wise organisation	Child Wise, Victoria <a href="http://www.childwise.org.au/page/37/online-publications">http://www.childwise.org.au/page/37/online-publications</a>	Not-for-profit child abuse prevention organisation	A risk management framework aimed at strengthening agency child safe standards through training and consultancy to enhance the safety and protection of children

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