



**Supporting children and young people with
a disability living in out-of-home care in
Australia**

Literature Review

Publication Edition

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Executive summary

It has long been recognised that children who cannot live with their families should benefit from the special care and assistance of the State (UN General Assembly, 1948, 1989). Australian child protection authorities provide this care and assistance through highly developed service models that are underpinned by legislation that reflect relevant human rights standards. However, it is unclear whether the care and assistance provided by Australian child protection authorities meets the needs of children with a disability. This literature review explores the support needs of children with a disability living in out-of-home care. It is intended that the review be used to inform policies about the provision of special care and assistance to children with a disability who come into contact with child protection systems within Australia.

The concept of 'disability' has been understood in different ways over time. For much of the 20th century the medical model underpinned the delivery of services to people with a disability. The medical model views 'disability' as a medical condition or illness which amounts to a deviation from biological or social norms and results in dependency (Murphy, O'Shea, Cooney, & Casey, 2007). This point of view has largely been discounted as a model for disability because it emphasises differences and serves to alienate people from the wider community (Scullion, 2010). However, despite being discredited, the medical model of disability continues to form the basis through which many people understand disability.

The social model of disability has largely replaced the medical model as the most widely accepted theory of disability (Humpage, 2007; Scullion, 2009). Under this model, 'disability' is viewed as an unequal social relationship that arises through negative perceptions towards a person's functional impairment (Connors & Stalker, 2007; Humpage, 2007; Roush & Sharby, 2011; Scullion, 2009). These unequal social relationships create barriers to a person's participation within their community. Under the social model, the goal of disability services is to overcome barriers to participation. This may include working to change community perceptions and assisting people to develop the knowledge, skills and abilities necessary to maximise their independence.

The principles of the social model of disability are reflected strongly in legislation, policy and practice across Australian jurisdictions. However, the model presents a number of challenges to researchers. Barriers to participation are difficult to define and observe (Cooke & Standen, 2002; Roush & Sharby, 2011; Scullion, 2009). This makes research into the prevalence of disability within service systems

difficult. Most research into the prevalence of disability relies on identifying individuals who experience impairments which require external support. The nature and severity of the impairments which qualify as a 'disability' vary significantly within, and across, jurisdictions.

The Australian Bureau of Statistics (ABS) measured disability in 2009 through a self reporting mechanism and found that an estimated 492,500 (6.8%) of children and young people aged under 25 were reported as experiencing a disability. That equates to almost 19% of the total community of people with a disability and 2.3% of the Australian community. The ABS has not measured the prevalence of children and young people with a disability living in out-of-home care.

Prevalence figures about the numbers of children with a disability living in out-of-home care vary widely. Some findings suggest that as few as 4% of children in care experience a disability (Jacob & Fanning, 2006). Jacob and Fanning (2006) do however suggest that figure is understated as it only includes those obtaining disability support services. Other research suggests that as many as 60-70% of children and young people in contact with the child protection system may experience some form of psychiatric disability (Minnis, Everett, Pelosi, Dunn & Knapp, 2006).

While it is generally accepted that children with a disability are overrepresented within child protection services little research has been conducted to identify the prevalence of children with a disability within out-of-home care. Child protection authorities do not apply a uniform definition of 'disability' and do not routinely capture information about a child's experience of disability within data collection frameworks. As a result, little empirical research has been conducted into the prevalence of children with a disability within out-of-home care in Australia. Published estimates about the numbers of children with a disability living in out-of-home care often rely on anecdotal evidence or rates of participation in specialist disability or education services. This limits the utility of the data and makes it extremely difficult to identify trends within, and across, jurisdictions.

This paper has adopted the definition of disability used in the literature in order to identify key issues, barriers and needed supports. It examines some key barriers that children and young people with a disability in care may face in the context of education and health. Drawing upon the literature, the review examines key health issues faced by children and young people with a disability in care and how factors such as placement instability, restrictive eligibility criteria for services and a lack of screening and assessment services may impact on health and well-being.



These factors are also identified as barriers to educational outcomes. The paper identifies a number of supports that may help children and young people with a disability to attain better education outcomes and minimise the potential for adverse factors being experienced in later life.

The literature highlights that the success of the child protection system can be measured by transition from care outcomes. It draws upon evidence that suggests young people ageing out of statutory care continue to transition without the benefit of a formalised plan and with little access to support. This situation appears to be exacerbated for young people with a disability who do not meet narrow eligibility criteria for disability services. As a result, many young people leave statutory care and find themselves without a carer, family support, and a place to live and without education and employment prospects. As a result, these vulnerable young people face a life of stress, struggle and estrangement.

1. Purpose

This paper reviews literature relating to the key support needs of children and young people with disability living in out-of-home care in Australia. It will broadly explore systems level issues and highlight key issues in the areas of health and education. It also identifies support that carers and caseworkers may require in order to better meet the needs of children and young people with disability in care. The paper also highlights the importance of including children and young people with disability in decision making processes and the importance of strategic and timely support services. Finally, the paper discusses the support young people with a disability need as they transition from care to adult life. It is anticipated that this literature review will be useful in informing policy makers about the support needs of children with a disability living in out-of-home care in Australia.

This review has not investigated programs or projects specifically aimed at supporting children and young people in care with disability. Nor has it systematically reviewed State and Territory based policies. This literature review is intended to give an overview of some key issues and challenges faced by children and young people with disability living in out-of-home care.

2 Introduction

2.1 Background

The number of children and young people in care throughout Australia is steadily growing (Australian Institute of Health and Welfare, 2012; McDonald, Higgins, Valentine, & Lamont, 2011). Increasingly, children and young people with high and complex needs are entering or are in the care system (Jacob & Fanning, 2006; Queensland Government, 2009; Sammut, 2011; Smyth & Eardley, 2008). Children and young people with a disability who live in out-of-home care are a particularly vulnerable group (Jackson & Muller, 2005; Nathanson & Tzioumi, 2007; National Council on Disability, 2008; Senate Community Affairs References Committee Secretariat, 2005). Evidence suggests that those with high support needs, extreme and complex challenging behaviour and/or impairments giving rise to significant disabilities are receiving inadequate levels of support (Jacob & Fanning, 2006; Smyth & Eardley, 2008).

Many children and young people are not being recognised as experiencing a disability (Committee on Child Abuse and Neglect & Committee on Children with Disabilities, 2001; Hibbard, Desch & Committee on Child Abuse and Neglect & Council on Children with Disabilities, 2007; Lightfoot, Hill & LaLiberte, 2011; Miller, 2003; National Council on Disability, 2008; United Cerebral Palsy & Children's Rights, 2006) and as a result, some children and young people with a disability living in out-of-home care may not be receiving appropriate or sufficient support. Prevalence figures about the numbers of children with a disability living in out-of-home care vary widely. Some findings suggest that as few as 4% of children in care experience a disability (Jacob & Fanning, 2006). Jacob and Fanning (2006) do, however, suggest that this figure may be understated as this figure only included those children and young people who were in receipt of formal disability support services. Other research suggests that as many as 75% of children and young people with high levels of placement instability may experience psychiatric disability (Osborn, Delfabbro & Barber 2008).

The social model of disability has largely replaced the medical model as the most widely accepted theory of disability (Humpage, 2007; Scullion, 2009). Advocates of the social model view 'disability' as an unequal social relationship that arises through negative perceptions towards a person's functional impairment (Connors & Stalker, 2007; Humpage, 2007; Roush & Sharby, 2011; Scullion, 2009). These unequal social relationships create barriers to a person's participation within their community. Under the social model, the goal of disability services is to overcome barriers to participation. This may include working to change community perceptions and assisting people to develop the knowledge, skills and abilities necessary to maximise their independence. However, the social model poses significant challenges for researchers attempting to track the prevalence of disability. This is because 'barriers to participation' are inherently subjective and difficult to observe.

In order to overcome the research challenges posed by the social model, researchers and Australian government authorities have largely assessed the prevalence of disability by observing the numbers of people who experience particular types of impairments and require a minimum level of support in key aspects of their day to day life (see Australian Bureau of Statistics, 2009; CREATE Foundation, 2006; Sullivan & Knutson, 1998, 2000). This approach to researching prevalence is inconsistent with the social model and is likely to result in an underestimation of the number of people who experience a disability (see Jacob and Fanning (2006); United Cerebral Palsy & Children's Rights, 2006). This is particularly relevant to child protection authorities across Australian jurisdictions where inconsistent definitions of

disability, and differing methodologies, have resulted in wide variance about the rates of disability reported and make it impossible to identify and track prevalence trends by reviewing existing literature.

Despite the challenges of researching the prevalence of children and young people with a disability living in out-of-home care it is generally accepted in Australia, the United Kingdom and the United States of America that this cohort is overrepresented (Cross et al., 1992; Miller, 2003; Nathanson & Tzioumi, 2007; National Council on Disability, 2008; Rosenberg & Robinson, 2004; Scherr, 2007; United Cerebral Palsy & Children's Rights, 2006). Children and young people with disability, their carers and families require support in order to best meet their needs (AIHW, 2002; Rous, Hallam, Harbin, McCormick and Jung, 2007; UN General Assembly, 2007). Child protection investigators and caseworkers need to possess skills in recognising, and responding to, disability (National Council on Disability, 2008; Shannon & Tappan, 2011).

It is widely recognised that there is a gap in the literature regarding children and young people in care with disability (Miller, 2003; Nathanson & Tzioumi, 2007; Tarren-Sweeney & Hazell, 2006; United Cerebral Palsy & Children's Rights, 2006). Despite this, research suggests that inadequate service responses to the disability support needs of children and young people in care can increase the risk of adverse consequences such as: frequent placement breakdowns and instability; being placed in a residential care setting as opposed to a family based placement; the development of extreme and complex challenging behaviour; and a lack of developmental opportunities. In their Academic Achievement Study, Greenen and Powers (2006) found that placement instability for children and young people with disability was significantly higher than that of their out-of-home care peers who did not experience a disability. Their findings also indicated that as the number of placements in foster care increase, grade point average (GPA) and performance in maths decreases.

It should follow that high quality services that meet the disability support needs of children and young people in care can reduce the negative effects of being placed in care. Branson and Bingham (2009) suggest that well planned life transitions, such as starting school or changing accommodation, can assist in promoting service continuity and reducing family disruption. Rous et al. (2007) suggest that a child's success in the next environment is the ultimate goal of a successful transition process. Service systems should be engaged in the life of children and young people with a disability in care from the very moment of entry, if not before (Jacob & Fanning, 2006; Shannon & Tappan, 2011). The transition into care is a major, and stressful, transition point. Effectively managing key transition points is a way that

can minimise the potential for children and young people to have negative experiences that may cause, or exacerbate, a barrier to their development and participation within their community (Branson & Bingham, 2009; Hetherington et al. 2010; Rous & Hallam, 2012).

Some transition points require less supports than others. Schulting, Malone and Dodge (2005) suggested that low intensity transition practices (planning and support) can positively impact academic outcomes and parent involvement in schools. For example, low intensity transition support might involve a support worker discussing a new program with a child and their family before the child starts to receive the service. Rous et al. (2007) reported that successful interagency collaboration at early transition points can result in positive attitudes toward school, increased academic skills and the active involvement of a child's family in their education.

3 Identifying children and young people with a disability living in out-of-home care

There is no consistently applied definition of 'disability' within Australia (Osborn & Delfabbro, 2005; Wallis Group, 1996). Researchers in Australia and overseas have recognised this as a major issue for children and young people for over 15 years (Committee on Child Abuse and Neglect and Committee on Children With Disabilities, 2001; Lightfoot et al., 2011; Manders & Stoneman, 2009; Osborn & Delfabbro, 2005; Smith, 2008; Spencer, Devereaux, Wallace, Sundrum & Shenoy, 2005; Sullivan & Knutson, 1998; Wallis Group, 1996). Cross jurisdictional differences are difficult to measure when the definitions identifying the target population differ. As outlined below, State and Territory legislation providing for the provision of disability services under the National Disability Agreement tend to define 'disability' narrowly and a nationally consistent definition of disability would assist in national data collection (Wallis Group, 1996).

All jurisdictions tend to identify incidences of impairment rather than barriers to participation when identifying people with a disability. Disability service legislation typically defines 'disability' as an attribute or impairment that is intellectual, psychiatric, sensory, physical (or a combination of those) that is or is likely to be permanent (*Disability Services Act 1993 (NSW)*, s 5; *Disability Act 2006 (Vic)*, s 3(1); *Disability Services Act 2006 (Qld)*, s 11; *Disability Services Act 2011 (Tas)*, s 4(1); *Disability Services Act 1993 (SA)*, s 3; *Disability Services Act 1993 (WA)*, s 3; *Disability Services Act 1991 (ACT)*, s 2; *Disability*

Services Act (NT), s 2). The jurisdictional differences tend to lie in whether the person's capacity is reduced, significantly reduced or substantially reduced with regard to one or more major life activities (communication, learning, mobility, decision-making or self-care) (See: *Disability Services Act 1993* (SA), s 3(c)(i); *Disability Services Act 1993* (NSW), s 5(1)(c)(i); *Disability Services Act 2011* (Tas), s 4(1)(c)(i)). These definitions may make it easier to measure whether, and to what degree, a person experiences a disability. These definitions are however different from that used in the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007). This definition recognises that disability arises from a combination of impairments and barriers that hinder full and effective participation in society on an equal basis with others (UN General Assembly, 2007). This measure is largely subjective and more difficult to measure. However, this broader definition is more inclusive and is consistent with the prevailing academic understanding of disability, the social model.

The way in which a decision maker defines or recognises disability will impact on whether a person is considered eligible to receive a range of specialist services and increased support (Shannon & Tappan, 2011). Sullivan & Knutson (1998) criticised the Westat (Cross et al., 1991) study because the definition of disability was based on the opinion of child protection workers – workers who were not trained and had no expertise in disability diagnosis. It is important that key decision makers, such as caseworkers understand the concept of disability and are able to facilitate assessment, planning and case management approaches that ensure children and young people with disability have access to the support they need (National Council on Disability, 2008; Shannon & Tappan, 2011). Where disability is viewed as a barrier to participation, rather than a medical problem, issues with prejudice, bias and stereotyping are more likely to be reduced and eliminated and appropriate supports and services are more likely to be accessible (Roush & Sharby, 2011; Scullion, 2009).

3.1 Caseworkers' perceptions of disability

Manders and Stoneman (2009) found that caseworkers who conducted investigations into the alleged maltreatment of children and young people were negatively biased against children and young people with disability. They sought feedback from 75 caseworkers throughout Georgia in the United States of America regarding 8 hypothetical scenarios involving either moderate or serious physical abuse to children with a) cerebral palsy; b) intellectual disability; c) emotional/behavioural disability; or d) no disability.

At both levels of injury severity (moderate or serious physical abuse), caseworkers were less likely to attribute blame for the abuse on the children without disability and attribute a higher degree of blame for the abuse on the children with disability (Manders & Stoneman, 2009). This was particularly the case for the children with cerebral palsy experiencing moderate abuse. That study also reported that the decision making of the respondent caseworkers was influenced by the severity of the child's injuries. Where the injuries were less severe the more the caseworkers tended to differentiate among disability groups and between cases involving children with and without disabilities. Even with more severe injuries, caseworkers tended to respond differently depending on the disability status of the child. This supports findings in the Westat study (Cross et al., 1992) that found 47% of caseworker reports were based on the view that the child's disability directly caused, or contributed to, their maltreatment. Manders and Stoneman (2009) suggested that investigation teams need to include disability specialists and that all caseworkers need to receive training in disability. They suggest that attitudinal changes are required to counteract the prevailing perception of disability as a cause of chronic stress and dysfunction.

There is very little evidence that suggests prejudicial attitudes do not exist in the Australian context. Llewellyn, McConnell and Ferronato (2003) investigated prevalence and outcomes data regarding parents with: a) psychiatric disability; b) drug and/or alcohol abuse; and c) intellectual disability, and the degree to which the children were the subject of a NSW care and protection order and placed in out-of-home care. They found an overrepresentation of children born to parents with intellectual and psychiatric disability in the child protection system. One perspective might suggest that parents with intellectual or psychiatric disability are incapable of looking after their own children. However, McConnell and Llewellyn (2002) suggest that children are being removed from parents with intellectual and psychiatric disabilities where "grounds for such removal are not related to protection of the child, but rather to misguided or prejudicial ideas about parents with intellectual disability" (2002, p. 298). Indeed, they suggest that the fact that parents with disability are presenting to court may be a result of caseworker's misunderstanding disability and holding unreasonable prejudicial beliefs.

Caseworkers, among others, need training and support so that they can recognise abuse indicators from children and young people with disability and make rational and objective decisions about each child's protective needs (Wallis Group, 1996). As reported by the Wallis Group in 1996, training Australian professionals, including out-of-home care workers, who are in contact with children and young people with a disability should enable them to detect the signs of abuse or neglect and know when appropriate

steps should be taken. In this way, the abuse and neglect of children and young people with a disability may be prevented. In their study the Wallis Group (1996) found that a number of agencies denied the existence or seriousness of children and young people with a disability being subjects of abuse and neglect. Miller (2003) suggested that “[o]rganisation and skills gaps between professionals working with disabled children and those in child protection create barriers to an effective child protection system” (2003, p. 22). He further suggested that this skills gap, in addition to the lack of effective interagency assessments and planning regarding children in the system can lead to a “failure to promote the child’s welfare, and a failure to identify early indications of possible abuse” (Miller, 2003, p. 22).

The American United Cerebral Palsy and Children’s Rights report (2006) suggested that insufficient training and support to ensure identification and assessment may result in underreporting, inappropriate placement decisions and inadequate provision of services for children and youth with disabilities in foster care.

4 Prevalence of children and young people with disability living in out-of-home care

An accurate and consistent definition of disability enables prevalence to be measured with greater accuracy and consistency (Wallis Group, 1996). Despite this, there have been studies that have attempted to capture prevalence. The Australian Bureau of Statistics (ABS) attempted to measure the prevalence of disability in Australia using a self reporting mechanism and found that approximately 6.8% of all children and young people aged under 25 experienced a disability/impairment (Australian Bureau of Statistics, 2009). The Australian Institute of Health and Welfare collects data on reported child abuse and neglect however has not yet conducted a national incidence survey and has not followed the recommendation of the Wallis Group in identifying disability in that incidence survey (Wallis Group, 1996, 22).

The Queensland Commissioner for Children and Young People and Child Guardian’s report *Views of Children and Young People in Foster Care 2010* found that 18% of young people, 17% of children and 23% of young children in foster care self reported that they experienced some form of disability (Fraser, 2010b). With reference to the ABS statistics it appears that children and young people with a disability are significantly overrepresented in the Queensland child protection system.

The CREATE Foundation (2006) found that 36.7% of respondents indicated they experienced either a medical condition and/or a disability. Approximately 14% of respondents reported experiencing at least 1 disability and almost 30% reported experiencing at least 1 medical condition. The report stated that “it seemed that in many instances there was little difference between what children and young people identified as a disability in contrast to a health condition” (CREATE, 2006, p. 10). The findings suggest that prevalence of disability in 10 to 17 year old children and young people in care may be much higher than the Australian average.

A 2006 study that defined disability according to Tasmanian disability services legislation found a comparably low prevalence of children and young people with a disability in care. According to Jacob and Fanning in their 2006 *Report on Child Protection Services in Tasmania*, there were 317 children being serviced by Disability Services in January 2006. Of these children, 117 (36.9%) were known to child protection services and 25 (21%) were on care and protection orders or voluntary care agreements. This equated to approximately 4% of the in care population at that time and is the lowest prevalence figure identified in the literature. Indeed Jacob and Fanning (2006) suggested the figures they reported are likely to be understated because the definitions used tend to eliminate many applicants for disability services thereby reducing the number of children and young people who were recognised as experiencing a disability.

The data used by Jacob and Fanning (2006) is the same data compiled through the National Disability Agreement National Minimum Data Set (NDA NMDS). The NDS NMDS collects information from disability service departments about people who have been deemed eligible to receive services under legislatively prescribed criteria. According to the Australian Institute of Health and Welfare’s website, NDA NMDS data is collected from users of disability support services and not from users of child protection services (Australian Institute of Health and Welfare, n.d.). The NDA NMDS is therefore of little help in determining the number of children and young people with a disability living in out-of-home care. The NDA NMDS is also limited by the fact that it cannot be used to identify the extent to which children and young people who are in the guardianship of the state have access to NDA funded services. It is apparent that there is a great need for both child protection and disability services authorities to work together to improve data collection relating to children and young people with a disability who are in contact with the child protection system (Wallis Group, 1996).

The Australian Senate Inquiry (2004) received a submission from the organisation Persons With Disabilities that suggested the prevalence of Australian children and young people in care with disability is approximately 40%. It was not reported how that figure was calculated. However, the 2004 NSW Ombudsman *Young People with Disabilities Leaving Statutory Care* report states that, according to the NSW Department of Community Services, the prevalence of children and young people with a disability in child protection services was 15%. According to that report the NSW Department used the following categories to identify and/or track disability in care:

- Developmental delay;
- Intellectual delay;
- Specific leaning/Attention Deficit Disorder;
- Autism, including Asperger's Syndrome and pervasive developmental disorder;
- Physical disability;
- Acquired brain injury;
- Sensory (hearing and speech);
- Psychiatric;
- Neurological including epilepsy and Alzheimer's.

However it is likely that there are children and young people who experience difficulties and barriers whose impairments are not identified within this list.

The 2002 *Victorian Audit of Children and Young People in Home Base Care Services* (Victorian Government, 2002) reported that approximately 20% of the 124 children and young people in temporary care at that time experienced a disability. That report did not identify a prevalence figure relevant to permanent care.

There is wide variance in the literature regarding the prevalence of children and young people with disability in care. The literature is consistent in suggesting that children and young people with disability in care are overrepresented in child protection services (Lightfoot et al., 2011; Rosenberg & Robinson, 2004; Sullivan & Knutson, 1998, 2000). However, research suggests that until a consistent approach is taken, the population who experience a disability are likely to be under reported (Hibbard et al., 2007; Lightfoot et al., 2011). Despite this, the literature does reveal some patterns regarding the types of impairments that some children and young people in care experience.

4.1 Recorded impairments in OOHC

The literature relating to types of disability experienced by children and young people in care appear to be as varied as the literature on prevalence. However, in both the 2008 and 2009 Queensland Commissioner for Children and Young People and Child Guardian's surveys, *Views of Young People in Residential Care*, approximately 26% of respondents reported experiencing a disability. The most prevalent forms of impairment reported were intellectual, learning and conduct disorders. In both the 2008 and 2009 reports, Attention Deficit Hyperactivity Disorder (ADHD) was the most commonly reported condition (approximately 14%) and learning impairments were experienced by approximately 14% of respondents (Fraser, 2008a, 2009). Approximately 9.1% of respondents in that study indicated they had an intellectual impairment. Asperger's syndrome, Tourette's syndrome, obsessive compulsive disorder, depression and stress disorders were also reported as significant conditions which often lead to children and young people experiencing barriers to equitable participation.

Of those reporting that they had a disability, approximately 65% indicated that they received special help due to their disability (Fraser, 2008a). Moreover, almost 24% indicated taking medications for other conditions including depression, sleeping disorders, bipolar, type-2 diabetes and epilepsy. It appears that most of the children and young people in the Commissioner's study who identified as having a disability may have experienced multiple conditions. The experience of multiple impairments is likely to increase the extent of a person's disability and their risk of experiencing poor outcomes in later life.

A study conducted by Osborn, Delfabbro and Barber in 2008 surveyed 364 children and young people aged 4 to 18 who had high levels of placement instability and lived in South Australia, Victoria, Queensland and Western Australia. Analysis of case files and caseworker interviews revealed that 75% of the study sample had conduct disorders. They also found that approximately 66% had problems communicating with their peers and 50% experienced clinical anxiety and/or depression. This is relatively consistent with Osborn and Delfabbro's 2005 study regarding the mental health status of children and young people referred to emergency, short term or long term placements in South Australia, Queensland and Western Australia who also experienced repeated placement instability. Osborn and Delfabbro's (2005) preliminary findings suggested that almost 70% of their sample had a conduct disorder and nearly 30% were diagnosed with ADHD. Of their sample, almost 28% reported a personality disorder or a mental illness and 12% identified as having a physical disability.

In 2006 Tarren-Sweeney and Hazell studied mental health status in foster and kinship care in NSW. They found that the children in their sample had exceptionally poor mental health and social competence. This is particularly disturbing given their sample only included children aged between 4 and 9 years old. Nathanson and Tzioumi (2007) found similar trends. However, their study was based on hospital health assessment records and was therefore wider in scope. They found that children and young people in care experience unacceptable levels of emotional health problems in addition to physical and developmental problems. Their study did not, however, focus on disability *per se*.

Minnis, Everett, Pelosi, Dunn and Knapp (2006) studied the emotional and mental wellbeing of children aged 5 to 16 residing in non-specialist (mainstream) foster care in the United Kingdom. They interviewed foster carers, teachers, biological family members and children and found that 60-70% of children and young people in care showed evidence of mental health problems and claimed that they were likely to be of clinical significance.

The 2001 Victorian study: *Findings of the Audit of Children and Young People in Residential Care* (Victorian Government, 2001), found that case managers reported that almost 38% of children and young people in residential care had been diagnosed with some form of mental health issue. Of this population, almost 16% experienced ADHD compared to a national average of 11.2% (Victorian Government, 2001). Likewise, almost 10% suffered from depression compared to a national average of 3.7% and approximately 8% experienced a conduct disorder compared to a 3% national average (Victorian Government, 2001).

The same study found that approximately 430 children and young people were residing in residential care in Victoria at that time. Of these, approximately 66% were aged 13 to 18 years of age, whilst 34% were under the age of 13. However, age distributions varied from region to region. Some regions reported having no children under 13 living in residential care. The Victorian residential care review found that 90 of the children and young people in residential care in 2000 experienced a disability. This consisted of 77 with an intellectual disability, 8 with a sensory disability and 5 with a physical disability. This equates to 23% of the children and young people in residential care in Victoria at that time. Moreover, the review found that 43% of young people aged 13 to 18 and 29% of those aged under 13 in residential care were diagnosed with a psychological disorder/disability.

These studies suggest that there is significant overrepresentation of children and young people with behavioural and/or emotional disorders in out-of-home care. Indeed, mental health conditions appear to be the most prevalent impairment in out-of-home care followed by intellectual and/or learning impairments. It is well recognised that children and young people with disability are a particularly vulnerable group who are at particular risk of experiencing abuse or neglect and subsequent entry into the child protection system (Lightfoot et al., 2011; Spencer et al., 2005; Sullivan & Knutson, 1998, 2000). It is less clear whether children with disabilities are predisposed to entering care or whether they are more likely to experience a disability because of past maltreatment and poor parenting practices. Tomison (1996) suggests that theories of maltreatment that focus on the child's characteristics may be a form of victim blaming which serves to create more barriers to a child or young person's participation.

5 Overcoming barriers to participation: Planning and coordinating care and protection services that are responsive to disability support needs

Children and young people in out-of-home care experience higher rates of physical, emotional, behavioural, learning and educational problems than their peers within the wider community. These types of issues pose significant barriers to a child's or a young person's ability to build and maintain socially valued roles within their community (Shakespeare, 2006; United Cerebral Palsy & Children's Rights, 2006). Research conducted by Nathanson and Tzioumi (2007) found that children and young people in care have unacceptably high health needs which often remain unidentified for long periods of time. Indeed, the 2006 report prepared by the United States of America based United Cerebral Palsy and Children's Rights partnership suggest that children and young people in foster care experience worse health than those who are homeless or living in the poorest sections of their inner cities. Spencer et al. (2005) suggest that children with specific impairments such as psychological problems, speech and language disorders and learning difficulties were significantly more likely to be registered with child protection services than their peers who did not experience a disability.

Disability support needs should be specifically designed for each child and young person. People are different in their aspirations, values and the forms of care that they need to enable them to develop and achieve their individual goals (Shakespeare, 2006). Improved planning and support service coordination for children and young people with a disability in care can improve their functioning (Queensland

Government, n.d.b). This, in turn, can positively impact placement stability, education involvement and outcomes, social engagement and their general state of wellbeing (Queensland Government, n.d.b).

5.1 Physical and mental health

5.1.1 The current situation

Children and young people placed in out-of-home care are at a higher risk of medical and health issues than their non-care peers (Clarke & Gwynne, 2011; Committee on Early Childhood, Adoption and Dependent Care, 2000, 2002; Nathanson & Tzioumi, 2007; United Cerebral Palsy & Children's Rights, 2006). Numerous studies have found that children in foster care have increased incidence of chronic health, developmental and psychological problems and that children and young people experiencing a disability appear to be particularly vulnerable to health complications (Chernoff, Coombs-Orme, Risley-Curtiss & Heisler, 1994; Committee on Early Childhood, Adoption and Dependent Care, 2000, 2002; CREATE, 2006; Nathanson & Tzioumi, 2007). In the 2004 report titled *Protecting Children: An Inquiry into Abuse of Children in Foster Care* (Queensland Government, 2004a), the Queensland Crime and Misconduct Commission relied on the evidence of Dr Jennifer Smith of the Royal Brisbane Hospital who reported that children entering foster care had "3 to 7 times as many acute and chronic health conditions, developmental delay, emotional adjustment problems as other children" (Queensland government, 2004a, p. 3).

In her 2008 report titled *Views of Young People in Residential Care*, the Queensland Commissioner for Children and Young People and Child Guardian found that almost 14% of the children and young people surveyed indicated that they suffered from ADHD (Fraser, 2008a). Interestingly, that same report found that 21.3% were taking medications commonly used to treat ADHD.

The *Report of the Special Commission of Inquiry into Child Protection Services in NSW* (2008) (Wood Inquiry) found that children and young people in out-of-home care in NSW were not receiving the medical, dental and allied health assessments and treatments they needed. Jacob and Fanning (2006) also state in their report that children and young people in out-of-home care are a highly vulnerable group with increased physical, mental, social and education health issues.

According to the United Cerebral Palsy and Children's Rights report "children who enter foster care with special needs, on average, have already experienced more than 14 different environmental, social,

biological and psychological risk factors before coming into care” (2006, p 5). The United Kingdom group highlighted the following statistics that suggest disability is the norm in child protection communities:

- 40% are born with low birth weight or born prematurely;
- 80% prenatally exposed to toxic substances;
- 30-80% experience at least one chronic medical condition (asthma, HIV, TB);
- 30-50% experience dental decay;
- 25% experience three or more chronic health problems;
- 30-60% experience developmental delays;
- 50-80% experience mental and behavioural health problems;
- 20% are fully handicapped; and only
- 30-40% receive special education services (United Cerebral Palsy & Children’s Rights, 2006, p. 5).

Trauma associated with the experience of abuse, neglect, dysfunctional family settings, being separated from parents and being placed in State care often have an adverse affect on a child or young person’s mental health. They are major stressors that can negatively affect the functioning of the body (Committee on Early Childhood, Adoption and Dependent Care, 2000).

Children and young people entering care often face significant health issues that can have a disabling effect and place barriers in front of them that may not exist otherwise (Shakespeare, 2006; United Cerebral Palsy & Children’s Rights, 2006). Child protection authorities need to identify the support needs of children and young people during the initial intake and case planning process to ensure that the services provided to each individual maximises their opportunities for development so that each is supported to reach his or her potential (Lightfoot & LaLiberte, 2006; National Working Group on Child Protection and Disability, 2003; NSW Government, 2005, 2003).

5.1.2 Early identification and assessment

The early identification of a disability and associated support needs can greatly reduce the risk of a child or young person experiencing adverse factors in later life (Lightfoot & LaLiberte, 2006; Shannon & Tappan, 2011). However, child protection authorities, with some exceptions, are typically poor at identifying such needs during initial intake, assessment and planning processes (Lightfoot & LaLiberte, 2006; Shannon & Tappan, 2011; Wallis Group, 1996). The Australian Research Alliance for Children and

Youth (ARACY), (2010) suggest we need to take a different approach in order to better protect children. They advocate for the active engagement of universal service providers, such as health practitioners, teachers and counsellors, child care workers and Centrelink staff, in responding to early signs of vulnerability. In doing so, assistance may be given to at-risk families before problems escalate into a crisis. The Australian Research Alliance for Children and Youth (2010) suggest that we need to speak of *protecting children* rather than *child protection* and that a needs based approach is preferable to existing, risk driven, approaches to assessment:

Identifying particular needs early and facilitating a link with appropriate support services should be seen as a normal process not associated with risk but instead associated with needs – a far different context for both provider and family (ARACY, 2010, p. 16).

The Australian Research Alliance for Children and Youth (2010) therefore suggested that a child or young person's development can be enhanced with early identification of need and early intervention to mitigate risk of harm. As Shannon and Tappan (2011) point out, caseworker identification of disability can increase a family's access to support services whilst also increasing safety and reducing the risk of maltreatment for a child or young person.

5.1.3 Substantiation and Assessment

Numerous studies have found that child protection workers who have not received specific training in disability theory and philosophy tend to view the child or young person's disability as a contributing factor in their alleged maltreatment (Cross et al., 1992; Manders & Stoneman, 2009; Wallis Group, 1996). Edwards and Richardson (2003) reported that the maltreatment of a boy with a disability was not substantiated because of the form and mode of medication he was required to take. Early identification of impairments and associated disability support needs can assist in determining whether, and to what degree, maltreatment is occurring (Shannon & Tappan, 2011; Wallis Group, 1996).

Shannon and Tappan (2011) investigated the ability of child protection screening and investigative processes to identify children with developmental disabilities. They found that most workers believed that almost 100% of children entering care had some form of developmental disorder. Their study produced evidence that the majority of children and young people with a disability were not being identified through initial screening and investigative processes. They found that child protection

caseworkers had not been educated or trained with disability specific theories and continued to struggle with the concept of developmental disability.

Children and young people with a disability may experience challenges in communicating maltreatment. Shannon and Tappan (2011) found that caseworkers often rely on family members to translate for the child or young person who is the subject of a child protection allegation. As Shannon and Tappan (2011) state, whilst child protection workers are “ideally placed to identify children in need of developmental services”... “the skills necessary to conduct developmental screening and assessment may be beyond what is reasonable to expect from CPS workers” (2011, p. 304). Once a decision is made that a child or young person should be taken into the out-of-home care system a second, more formal, assessment process should be conducted and this is usually in the form of a pre-placement health screening and health assessment.

5.1.4 Pre-placement health screening and health assessments

Once within the care system, it is in the interest of each child or young person for child protection authorities to facilitate a thorough pre-placement health screening and assessment (Committee on Child Abuse and Neglect & Committee on Children with Disabilities, 2001; Hibbard et al., 2007; Nathanson & Tzioumi, 2007; United Cerebral Palsy & Children’s Rights, 2006). Such assessments ensure that health issues are identified and that caseworkers can ensure that each child or young person has adequate access to health services during their time in care.

The need for pre-placement health screening is well evidenced within academic literature. Chernoff et al. (1994) examined the health issues of children and young people upon entry into foster care and those who had been in care for 2 years. They found that 90% of the children and young people had an abnormality in at least one part of their body. They also found that 25% had vision issues to such a degree that they failed their vision screen, whilst 15% failed their hearing screen. There is no doubt that the general population of children and young people do not experience such high rates of health issues. Indeed Chernoff et al’s. (1994) findings are comparable to those reported by Nathanson and Tzioumi (2007).

Nathanson and Tzioumi (2007) reported on the health assessment outcomes of 122 children and young people aged under 12 years who were assessed at the Child Protection Unit of the Sydney Children’s

Hospital since February 2005. Of the children referred to the Hospital by the Department of Community Services: 20% failed their vision screen; and 26% of those who had a hearing test failed that test. Of the children aged under 5 who were assessed, 45% were found to have speech delay. Twenty percent of the older children had delayed language skills. Nathanson and Tzioumi (2007) also reported that 54% of children and young people presenting for health assessments presented with behavioural and emotional issues. The common themes were grief and loss, separation and attachment issues. However, the study was limited by the fact that researchers did not use standardised assessment tools to identify emotional and behavioural problems.

Health screening and assessment is identified in the Australian National Standards for Out-of-Home Care (Australian Government, 2011a). The Standards require that health assessments and attendances occur in a timely way and the National Clinical Assessment Framework states that a preliminary health check should commence no later than 30 days after a child enters care (Australian Government, 2011b). Nathanson and Tzioumi (2007) report that 22% of the children and young people they assessed had been in care for less than 1 month and 55% of those assessed had been in care between 1 and 6 months. Guarino, Buddin, Pham and Cho (2010) found that children with a disability entering foster care in California are much more likely to have their special needs identified than those living with their biological parents. They suggest that this is due to a case system where all children and young people are automatically screened and assessed by a physician as they enter out-of-home care. This is not uniform practice across Australian jurisdictions (see Nathanson & Tzioumi, 2007; Wood, 2008).

Most children and young people in care do not receive health screening or assessments (Wood, 2008). In Australia, screening tends to occur only where the caseworker or carer has identified a possible health issue (Nathanson & Tzioumi, 2007). Most child protection caseworkers do not possess specialist or professional expertise in working with children who have a disability (Lightfoot & LaLiberte, 2006; Sullivan & Knutson, 1998).

In the Child Protection Unit of Sydney Children's Hospital, assessments are performed by a paediatric doctor and either a social worker or psychologist (Nathanson & Tzioumi, 2007). However, Nathanson and Tzioumi's (2007) study found that dental health status for the foster care cohort (33%) was similar to the wider Australian population for the same age group. Nathanson and Tzioumi (2007) suggest that the dental health findings may be a result of the assessment team lacking dental expertise.

The American United Cerebral Palsy and Children's Rights (2006) report suggests that screening should be conducted within 24 hours of entering care. They suggest that a comprehensive assessment should be conducted within 30 days. Moreover, they suggest that dedicated Foster Care Clinics, where paediatric healthcare professionals who understand the effects of foster care on children should provide the screening and assessment. The report also suggested that this would universalise the medical home model and enable the better management of medical records. The Committee on Early Childhood, Adoption and Dependent Care (2002) appears to support these timeframes for screening and assessment.

An effective and accurate health assessment requires information relevant to the child or young person's past. The Committee on Early Childhood, Adoption and Dependent Care (2002) states that it is imperative that complete health and development histories are available to the paediatrician at the time the assessments are conducted. Nathanson and Tzioumi (2007) agree that past medical and family history is central to a comprehensive health assessment. However, Nathanson and Tzioumi (2007) caution that accessing such records may be difficult where a child's parents are not accessible or are unwilling or unable to provide information. Their study found 14% of children and young people had no access to parental information about their health history, no available health record (blue book) and no relevant information recorded on the Australian Childhood Immunisation Register.

The United Cerebral Palsy and Children's Rights (2006) report also identified the necessity to adopt, and meet, healthcare standards for children and youth people in care that are consistent with those put forth by the Child Welfare League of America (1988), the American Academy of Paediatrics (1994, 2002) and the American Academy of Child and Adolescent Psychiatry (2001) (cited in Halfon, Zepeda & Inkelas, 2002; cited in United Cerebral Palsy and Children's Rights, 2006). These bodies suggest that all children should also receive mental health screening when entering care and receive a mental health assessment within a month of being placed in care (Halfon et al., 2002).

5.1.5 Disability Assessments

The understanding of disability as barriers to a person's participation in their community requires a different form of assessment than pre-intake health screening. Such assessments should focus on identifying the disability supports and services that an individual requires to assist them to undertake the activities that will enable them to maximise their participation in their community.

Riches, Parmenter, Llewellyn, Hindmarsh and Chan (2009) investigated ways to effectively classify and assess the support needs of people with disabilities. They described disability as a dynamic state in which a person experiences restricted functioning due to the interaction of the person (including their impairment), the activities they want to do (including any difficulty experienced in carrying them out), environmental and personal factors (including barriers to participation caused by factors such as physical access and discriminatory attitudes). The provision of supports to improve everyday life, functioning and to empower people to live the life they choose can assist in overcoming barriers and should be the goal of every service that seeks to assist a person with a disability (Riches et al., 2009).

Traditionally, disability assessments have not aimed at identifying support needs. Rather, the focus of assessment has been on identifying the nature of an individual's impairment and associated deficits (Guscia, Harries, Kirby, Nettelbeck & Taplin, 2006). For the most part, this was measured by determining the absence of adaptive behaviours and the presence of maladaptive behaviours (Guscia et al., 2006). Therefore, the focus of such assessments has been on the treatment needs of the individual rather than the daily support they require to overcome functional impairments and to participate in their community (Guscia et al., 2006). Researchers, government authorities and service providers are now exploring ways in which the support needs of people with a disability can be reliably assessed.

In 2002, the Australian Institute of Health and Welfare (AIHW) identified that there was wide variance across Australian jurisdictions relating to the assessment of support needs for people with a disability. Disability services have made significant improvements in the way in which support needs are assessed during the years since the AIHW finding. However, the assessment of disability support needs remains an area of concern within child protection systems.

Typically, child protection workers are not trained or equipped with specialist knowledge about the provision of disability services (Manders & Stoneman, 2009; Shannon & Tappan, 2011). The focus of such professionals is, and should be, that the care and protection needs of children and young people are being met. Such workers require the support of other professionals to ensure that each young person's care plan adequately identifies, and seeks to meet, their individual needs (Manders & Stoneman, 2009).

Multi-disciplinary assessment enables professionals from a number of disciplines to contribute to the process. This enables assessment results and recommendations to incorporate a number of different professional viewpoints. Multi-disciplinary assessment is particularly useful when addressing the needs of people with complex needs. Guscia et al. (2006) found that the presence of multiple disabilities was positively correlated with increased supports needs. It follows that it is highly desirable that children and young people, who are suspected of having a disability, receive a comprehensive multi-disciplinary assessment when they enter out-of-home care. Such an assessment informs case planning and assists in greatly reducing the risk that a child will experience adverse outcomes in later life.

Multi-disciplinary assessments and recommendations should empower the child. That is, assessments and recommendations should be based on listening to a child, focussing on what is important to them and acting upon this information in an alliance with their family and friends (Sanderson, 2000).

According to Callicott (2003), child centred planning should:

- Focus on the child and who they are;
- Concentrate on the aspirations, hopes and dreams the child has for their future life;
- Actively involve family and friends;
- Allow the child to participate in, and where possible lead, assessment and case planning processes; and
- Value achieving genuine social inclusion and community participation.

Woods and McCormick (2002) also suggest that, where appropriate and practicable, the assessment of disability support needs should be family centred. This approach involves engaging family members in the assessment process and supporting them to make responsible and informed decisions (Woods & McCormick, 2002). Under this framework, family members are central to identifying problems and coming up with possible solutions. By engaging family members in the assessment process it is more likely that they will actively attempt to implement professional recommendations within the home environment.

Some Australian child protection authorities have made significant steps towards introducing multi-disciplinary assessments to identify the disability support needs and inform case planning for children and young people entering out-of-home care (see the Evolve program developed in Queensland; Queensland Government, n.d.b). However, many jurisdictions appear to lack any consistent framework for identifying the disability support needs of children and young people entering care.

5.2 Education

5.2.1 The current situation

Quality education outcomes are directly linked to economic sufficiency and the ability to provide for oneself. Education is a key determinant of future quality of life. Possession of a tertiary degree is associated with better health, more meaningful employment and higher economic status (Day, Riebschleger, Dworsky, Damashek & Fogarty, 2012). It is well established that children and young people with a care experience have lower education outcomes than their peers (Day et al., 2012; Kessler, 2004; National Council on Disability, 2008). In her 2010 report, *Views of Children and Young People in Foster Care*, the Queensland Commissioner for Children and Young People and Child Guardian found that almost 60% of children interviewed by her office reported problems with school work (Fraser, 2010b).

Some researchers suggest that up to 40% of the child protection community may be eligible for special education services, yet only a small fraction of this group actually receive the education they require (Cross et al., 1992; National Collaborative on Workforce and Disability for Youth, 2007; National Council on Disability (2008); United Cerebral Palsy & Children's Rights, 2006). According to the United Cerebral Palsy and Children's Rights (2006) report, one reason for this is that children and young people living in out-of-home care tend to lack a consistent educational advocate. They state that all too often "birth parents are not included in educational planning activities; foster parents do not understand the importance of their role; and case workers do not have the time to participate in regular meetings" (United Cerebral Palsy & Children's Rights, 2006, p. 7).

It is not surprising that moving from one school to another can disrupt educational outcomes. On average a young person in care may go to between 3 and 7 different schools (National Council on Disability, 2008). In their discussions with youth, Greenen and Powers learned that young people in care with disability were being awarded modified educational certificates compared to their peers with a disability who were not in care (Greenen, Powers, Hogansen & Pittman, 2007). They found that many young people in care with severe disabilities were missing credits because key coursework had not been completed.

Missing coursework is not necessarily a result of experiencing a disability but does appear to be closely related. Greenen and Powers (2007) found a positive correlation between incomplete coursework, a high number of school changes and placement instability. The Queensland Department of Communities' 2009 *Transition and Post Care Support Program Operational Practice Manual* suggests that placement instability is a common experience for the majority of children and young people with a disability in care. This instability is likely to significantly affect educational outcomes.

The National Council on Disability (2008) suggests that with each change of school, 4 to 6 months of educational attainment may be lost. The Council states that the rate of tertiary enrolment and graduation for young people with a disability who have been in contact with child protection services is low. Greenen and Powers (2006) found similar trends. Their study found that young people living in foster care and in special education had lower academic performance compared to control groups. Greenen and Powers (2006) investigated the academic performance of 327 students aged 13 to 21 and compared academic performance between a number of groups (foster care and special education, foster care only, special education only, general education only and a control group). They found that young people in foster care who were receiving special education tended to perform poorly, compared with the control group, when completing academic tasks. They also found that young people living in foster care and enrolled in special education programs received the most restrictive special education placements. They concluded that the synergy of the education and child protection systems may serve to compound the educational disadvantages facing this group.

5.2.2 School support teams

A child's behaviour can be influenced and shaped by the expectations of others and the manner in which they are treated. According to the American National Council on Disability (2008), attitudes towards special education in the United States have changed dramatically since the 1990's. This has involved a change in focus from ensuring children and young people with a disability have 'access to education' to 'expecting a particular academic standard'. According to the Council, this has produced positive academic and social outcomes. The Council suggests that these positive changes have also been caused by:

- Placing more students with disabilities into the general education curriculum and exposing them to grade-level coursework;
- Measuring more students with disabilities with grade-level assessments;

- Increasing the exposure of students with disabilities to highly qualified teachers; and
- Increasing the expectations of educators and the community about their ability to meet proficiency in core academic subjects (National Council on Disability, 2008, p. 62).

The National Council on Disability (2008) also suggest that school counsellors are key supports for teachers and children alike. It is widely recognised that school counsellors and student support services can increase academic outcomes (National Council on Disability, 2008; Sink & Stroh, 2003; Webb, Brigman & Campbell, 2005). According to the National Council on Disability (2008), school support teams and school counsellors can also assist with goal setting and transition planning. However, the National Council on Disability (2008) suggested that such support services are under resourced. They report that in the United States there are between 3 and 50 times as many students assigned to school counsellors than the profession considers appropriate. The Council also highlights that schools in low income areas tend to have less resources and this includes higher student to counsellor ratios.

The American School Counsellor Association recommends a counsellor to student ratio of 1:250 (Carrel & Carrel, 2006). In an investigation conducted in Florida, Carrel and Carrel (2006) sought to determine whether lower student to counsellor ratios would reduce repeated behavioural disruptions and subsequent disciplinary action in elementary schools. They found that disciplinary recurrence was reduced by 7.4% when the (mean) average student to counsellor ratio was reduced from 544 students per counsellor to 250 students per counsellor. Moreover, the recurrence of disciplinary action reduced by 25.5% when the effects were examined within a given school year. This suggests that children and young people with conduct and behavioural problems may benefit from lower counsellor to student ratios.

In Australia, counsellor to student ratios vary from jurisdiction to jurisdiction and are influenced by whether a school is public or private/independent. In 2008, the ratios across Australian jurisdictions were much higher than those in the Carrel and Carrel (2006) study. However, it is not known whether, and to what degree, the duties and tasks of the counsellors in each context are equivalent. According to the AGCA National Executive, Australian counsellor to student ratios in 2008 were as follows:

- 1: 2,500 in the Northern Territory for Government schools. Non-government schools were not recorded;
- 1:1,050 in New South Wales for Government schools. Non-government schools were not recorded;

- 1:1,300 in Queensland for Government schools;
- 1:350-900 in Queensland for non-Government and Independent schools;
- 1 Guidance Officer for every 3,779 students in South Australian Government schools;
- 1 Early Education Psychologist for every 1,944 students in South Australian Government schools;
- 1:1,800 in Tasmanian Government schools; and
- 1:1,200-2,000 in Western Australia's Government schools.

According to the Australian Education Union, ACT Branch (n.d.), the recommended ratio is 1:918 for Government schools. Based on this recommendation, and in comparison with the US, it appears that Australian schools may not be providing adequate levels of counselling support and guidance to students. This may have a significant impact on academic outcomes for children and young people with a disability in care. This may be exacerbated where counsellors and teachers do not have an understanding of disability or the complex challenges faced by children and young people in care (National Council on Disability, 2008).

6 Supports required whilst in care

6.1 The right support at the right time

Support services for children and young people with a disability are only effective if they are provided in a timely manner and are responsive to the individual needs of each person. Providing timely and contextual support is dependent on an accurate assessment of a person's disability support needs. Children and young people with a disability are likely to require increased, or additional, services in response to key times of transition or change. Such times include changing accommodation; starting or changing school; entering the child protection system; being reunified with parents and changes in key support staff (Committee on Early Childhood, Adoption and Dependent Care; 2000; Rous, et al., 2007).

Child protection literature often uses the term 'transition' to describe the process of a young person moving from statutory care to independence and adulthood. However, the term 'transition' is used in a broader sense within this section of the paper to describe a child's experience of significant change.

Transition points can be viewed as “points of change in services and personnel who coordinate and provide services” (Rice & O’Brien, 1990, as cited in Rous & Hallam, 2012, p. 232; see also Branson & Bingham, 2009). However, as Rous and Hallam (2012) point out, that definition does not take into account age based factors. They tend to prefer the approach used by Kagan (1992) that describes transition as involving two types of change in services or programs. They suggest that vertical transition represents changes over time (early intervention to preschool, primary school to high school); and horizontal transition as that which occurs within a fixed period of time (a week, a day). They suggest that either type of transition can have negative impacts on a child or young person particularly if it is not well managed.

Topping (2011) suggests that whilst considerable research has been conducted on the transition from school to work, less has been conducted on the transition from primary to secondary school and even less on the transition from nursery to primary school. This is interesting given the formative importance of the first 5 years of a person’s life and the potential that negative events during this time may lead to lifelong experiences of adversity (Rous et al., 2007).

The transitions that occur in the first 5 years of a child’s life can be stressful, inefficient and problematic for children with a disability, their families and agencies involved in the process (Rous et al., 2007). Rous et al. (2007) suggest that the experience of moving from one program to another can be accompanied by variability in service delivery models, differing perspectives about family participation and changes in the quality of the program. They suggest that an increase in the number of programs for children with disabilities does not necessarily equate to improved effectiveness. Supporting children (and their families) to transition from one program to another through quality case planning and support is more likely to increase a child’s transition and their ability to adapt to the new environment.

There appear to be well accepted transition markers in the literature that can assist governments to identify the points at which a child or young person with a disability in care may need extra support. Given the accepted definition of a successful transition is the child’s success in the next environment (Rous et al., 2007); key transition points can be identified by major environmental changes. Rous et al. (2007) identified a key transition point for young children as their movement from pre-school into the primary school system. Transitioning from the family into care and changing placements are also likely to be key transition points (as defined by Rice & O’Brien [1990, as cited in Rous & Hallam, 2012]) for children and young people in care that require increased support.

6.2 Specialist behavioural intervention

Over the last three decades Positive Behaviour Support (PBS) has emerged as the predominant approach for understanding and addressing problem behaviours. Positive Behaviour Support emerged from the theory of Applied Behaviour Analysis (ABA) but has, over time, expanded to incorporate a broader range of theories. (Dunlap, Carr, Horner, Zarccone & Schwartz, 2008).

Professionals and service providers who seek to address problem behaviour through PBS seek to understand the function that a behaviour serves for a person before applying multi-component interventions to ensure that the person's needs can be met in a more adaptive way. Such interventions may include the manipulation of ecological and setting events, addressing antecedent events, teaching adaptive behaviour, building environments with effective consequences and minimising the use of punishers. Positive Behaviour Support distinguishes emergency procedures from proactive programming, promotes social validation and seeks to preserve the dignity of the recipients of interventions (Horner, Dunlap, Koegel Carr, Sailor & Anderson, 1990).

The values and theories of PBS are now strongly reflected across disability service systems in Australia. However, child protection systems throughout Australia continue to draw criticism for providing inadequate behaviour support services to children and young people living in out-of-home care. In 2008 the Wood Inquiry found that:

Foster, kinship and relative carers should be supported in caring for children and young people, including assistance to work with those with challenging behaviours, to improve the stability of placements. This should include access to regular and planned respite care, behavioural management support, and other evidence based specialist services (Wood, 2008, vi).

The Wood Inquiry (2008) finding followed a similar recommendation in Queensland. In 2004 the Queensland Crime and Misconduct Commission Report *Protecting Children: An Inquiry into abuse of children in foster care* (2004a) recommended that "more therapeutic treatment programs be made available for children with severe psychological and behavioural problems", with an emphasis that "successful programs be identified, implemented and evaluated" (Recommendation 7.5).

The Crime and Misconduct Commission recommendation was endorsed by the Queensland Government and set out in the *Blueprint for implementing the recommendations of the January 2004 Crime and Misconduct Commission Report "Protecting Children: An Inquiry into the abuse of children in foster care"*. The Queensland Government implemented the recommendation by introducing the Evolve Interagency Service. The Evolve initiative has established specialist multi-disciplinary teams throughout Queensland to provide assessment and PBS services to children and young people living in out-of-home care (Queensland Government, n.d.b). Evolve teams provide specialist disability assessments to children entering out-of-home care to inform case planning. Evolve teams also provide specialist behaviour intervention services to children with complex challenging behaviour. These services reflect the values, principles and theories of PBS (Queensland Government, n.d.b).

There is a need for all Australian jurisdictions to ensure that the behaviour support services that they provide to children and young people with a disability in care are consistent with the accepted best practice standards identified within the literature.

6.3 Carer Supports

6.3.1 General supports and requirements

Over the last 10 years the number of children and young people entering care in Australia has steadily increased whilst the number of foster carers is decreasing (Australian Foster Care Association, 2004). The Australian Foster Care Association (2004) states that children and young people with disability who have experienced abuse and neglect require specialised care from highly skilled and well-supported foster carers. They suggest that the needs of children and young people with a disability are often better served by experienced and trained carers and therapists than by workers who have not received specialised training in disability.

A recent Canadian study by Brown and Rodger (2009) focused on the problems encountered by foster carers who supported children and young people with a disability and identified problems associated with:

- Obtaining specialised professional services;
- Increased costs associated with fostering a child with a disability;
- Having time and opportunities for themselves;

- Managing multiple roles; and
- Dealing with the health care system.

A study conducted by Brown, Moraes and Mayhew (2005a) in Canada asked 44 foster carers of children with disabilities 'What services or supports would be helpful to you'. The major items carers identified in that study were:

- More support in the community;
- Peer support groups;
- More integrated recreational and education opportunities for the children;
- Financial support;
- Better educational supports for children with disabilities and good special education programs;
- Understanding and supportive social workers who return phone calls;
- Information about the child's history and medical information;
- Training on Indigenous culture;
- More information about disabilities generally and the particular impairments and disabilities relevant to their child in care;
- Therapies such as music therapy, occupational therapy, speech therapy and play therapy; and
- Respite care.

Another study conducted in Canada by Brown, Sigvaldason and Bednar (2005b) found that foster carers of children with Foetal Alcohol Syndrome required, among other things: social supports; material supports; a structured home environment; access to professionals and other foster carers; and an understanding of Foetal Alcohol Syndrome.

A 2004 report developed for the NSW Department of Community Services (McHugh et al., 2004) stated that carers tend to be motivated to continue fostering because of the individual child in their care. Apart from poor health, old age, the arrival of a new baby and changing work commitments, NSW foster carers in 2004 tended to cease fostering due to burnout, lack of support, the negative effects of fostering on the carers family and children being too difficult to care for (McHugh et al., 2004).

McHugh et al. (2004) also found that carers want support from caseworkers and that a lack of regular casework and regular caseworker visits to carers was strongly associated with placement breakdown and thus placement instability. They found that a lack of honest information sharing from the

department could detriment a carer's ability to cope with the child in their care particularly with regard to a child's medical history, behavioural problems, placement and schooling histories and family background. Many carers were concerned that the degree of disability or special needs of a child was not fully explained to them prior to placement. Only 51% of the carers surveyed responded that they had been provided with adequate information about the child or children who was placed with them.

According to the Australian Foster Care Association (2004) many carers of children with disability are financially disadvantaged. They suggest that foster carers often contribute to the cost of equipment, altering their homes and the extra costs associated with enabling the foster child to fully participate in family life. They also suggest that the additional time associated with caring for a child or young person with a disability reduces the carer's opportunity for paid employment. McHugh (2002) also investigated the costs of foster care in Australia and identified a number of financial stressors. She found that foster carers were paid an amount of money that did not adequately cover the child or young person's requirements. She also found that kinship carers were paid at a higher rate than foster carers; that there were often difficulties organising and receiving reimbursements for additional services; and that they relied heavily on the public health system. McHugh (2002) suggested that children with complex needs or a disability may experience 6 to 12 month delays which may negatively impact on their health, education and development.

6.3.2 Training carers in special needs

Placement instability and disruption is often caused by an inability to cope with the stress of caring for a child or young person in care. Research suggests that a lack of foster parent training can increase family stress and the rates of placement disruption (Greenen & Powers, 2007). The challenges of meeting the care needs of a child or young person with a disability can lead to carers experiencing significant levels of stress. The Australian Foster Care Association (2004) suggest that it is vital that children and young people with disability are cared for by specialised foster carers.

Research conducted in 2005 in Queensland found that approximately 50% of foster carers had not completed any pre-service or induction training prior to the placement of a child or young person with them (Butcher, 2005). In that study, Butcher (2005) found that 35% of carers subsequently underwent training (post placement) but that 15% never received any form of training. Brown et al. (2005a) found that foster carers of youth with disabilities lacked knowledge relevant to the specific disability of the child they cared for. This was also reflected in the 2004 Queensland Crime and Misconduct Commission

report which stated that, in some communities, training for carers was non-existent or inappropriate. The Commission also highlighted the need for specific training for carers of children with disabilities and special needs.

Six years later, the 2010 Northern Territory report titled *Growing them Stronger, Together* found that approximately 33% of foster carers were 'available' to care for children with disabilities.

In South Australia, the 2008 Commission of Inquiry (Mullighan Inquiry) also found that carer training was lacking. The Commissioner recommended, among other things, mandatory specialist training for all carers and potential carers of children and young people with disabilities (Mullighan, 2008). The Commissioner emphasised the need to train carers to respond to sexual abuse experienced by children and young people with a disability. Tasmania expressed its intention to follow this initiative in its 2008 publication titled *New Directions for Child Protection in Tasmania: An Integrated Strategic Framework*. This document stated that the special recruitment of carers should be considered and additional training and support would be required.

Family based care provides the best opportunity for children to develop and reach their potential (UN General Assembly, 1989). However, children and young people with a disability are significantly overrepresented in residential services (Flynn, Ludowici, Scott & Spence, 2005; Victorian Government, 2001). The interests of children and young people with a disability would be served by all jurisdictions introducing strategies to ensure that children and young people with a disability have equitable access to family based placements. This could be achieved through strengthening the level of support available to foster carers who care for a child or young person with a disability.

7 Transition to independence and adulthood

7.1 Why plan for transition from care?

Leaving care can be a daunting prospect for children and young people in care who are reaching the upper age limit of the statutory care period. After turning 18, young people leaving care often have little access to formal support services and find themselves living in isolation and estranged from their community (National Working Group on Child Protection and Disability, 2008). Most jurisdictions have passed legislation providing for this major transition point and acknowledge the need for young people to continue to have access to services and support beyond statutory care (*Children and Young Persons*

(Care and Protection) Act 1998 (NSW) s 165; Care and Protection of Children Act (NT), ss 68, 71; Child Protection Act 1999 (Qld) s 75; Children, Youth and Families Act 2005 (Vic) s 16 provides for transition assistance up until the age of 21; Children and Community Services Act (2004) (WA), s 96).

In practice, and despite legislative requirements, most young people leave statutory care without experiencing the benefit of a planned transition (McDowall, 2011). This places children and young people with a care experience at greater risk of homelessness, lack of educational attainment, underemployment, economic hardship, poverty, early and unwanted pregnancy, drug and alcohol abuse and engagement in the criminal justice system (Cross et al., 1992; Edwards, 2010; Gil-Kashiwabara et al., 2007; Greenen & Powers, 2007; Jackson, O'Connor & Cenoweth, 2006; National Collaborative on Workforce and Disability for Youth, 2007; National Council on Disability, 2008; Queensland Government, 2009; Smyth & Eardley, 2008; United Cerebral Palsy & Children's Rights, 2006). Without interagency engagement and the development of an effective transition plan, the risks of alienation, estrangement and isolation are even greater for young people with a disability (White et al., 2009).

Young people with a disability face additional barriers in their transition from care to adulthood and independence (Greene & Powers, 2007). It is vital that all young people with a disability receive transition planning and support before leaving statutory care and the safety net of caseworkers and carers. The NSW Ombudsman (2004) stated that the success of a young person with a disability who is in the process of transitioning from care to self-sufficiency is dependent upon effective planning which needs to commence well in advance of the young person's 18th birthday. The Ombudsman found that for one young Aboriginal woman with an intellectual disability, transition planning commenced only weeks prior to her 18th birthday. Moreover, the Ombudsman found that her first case conference was held only 4 days before her birthday. The report does not state how long she had been in care for but it does highlight the need for child protection authorities to better respond to the transition needs of young people in care – particularly those with a disability.

Young people leaving care may require access to mental health support services (White et al., 2009). Research suggests that foster care alumni with physical and/or psychiatric disabilities had significantly lower economic and health outcomes than their peers without disability (Anctil, McCubbin, O'Brien, Pecora & Anderson-Harumi, 2007). Anctil et al. (2007) also found that people with a disability who had been in foster care reported lower educational attainment, experienced more difficulties paying monthly bills, were more likely to have a psychiatric diagnoses, had lower self esteem and had worse

physical health than people who had been in foster care but did not experience a disability. White et al. (2007) suggest that young people need, among other things, effective employment training and job experience in order to reduce the rates of depression among care leavers.

Research conducted in NSW found that 57% of young people had contemplated suicide 12 months after statutory care ended (Cashmore & Paxman, 2007). Thirty-three percent had acted upon such thoughts and had attempted suicide (Cashmore & Paxman, 2007). Cashmore and Paxman (2007) also found that within 4-5 years of leaving care, 71% of young people had contemplated, attempted or committed suicide. This strongly suggests that many young people are not coping with the transition to adulthood and require access to a range of additional support services.

In the United States, the National Collaborative on Workforce and Disability for Youth (2007) suggested that almost 80% of adults formerly in foster care had significant mental health conditions. In their study, 25% of young people transitioning from care experienced post traumatic stress disorder (PTSD). A 2005 study found that 50% of young people had sought mental health assistance and support within 6 months of leaving care (Raman, Inder & Forbes, 2005). Without access to specialised support services, young people with a disability leaving care are at extreme risk of homelessness and a range of other adverse outcomes. Greenen and Powers (2007) found that professionals and foster parents were particularly concerned about access to services for young people who did not qualify to receive adult disability services. Young people with a slightly higher functional ability who do not qualify for disability services and supported living programs, but nevertheless face complex challenges and barriers to participation, can easily find themselves homeless (Greenen et al. 2007). Supports for this major transition point need to be planned and implemented well before a young person exits statutory care.

The 2007 study by Greenen and Powers may go some way to explain why the transition to adulthood is so difficult. Greenen and Powers (2007) highlighted a 'frustrating paradox' where young people "have little or no opportunity to practice skills of self-determination while in care, but are expected to suddenly be able to control and direct their own lives once they are emancipated" (Greenen & Powers, 2007, p. 1090). Many of the respondent young people in that study expressed frustration that caseworkers and carers were making decisions for them but not letting the young person be a part of the decision making process. In this way, those young people were not given the space to make their own mistakes and therefore were not learning by their mistakes whilst in a safe and secure environment. In that study, Greenen and Powers (2007) found that many "child welfare professionals

explicitly agreed that giving young people more opportunities to take responsibility and ownership for their lives is key to successful transition” (Greenen & Powers, 2007, p. 1090). The United States National Resource Centre for Youth Development (Kessler, 2004) also identified the need to develop self-determination, communication and problem solving skills to empower young people who are leaving care.

7.2 Extent of planning

In 2009-10 a total of 2,695 young Australians aged between 15 and 17 left State care (AIHW, 2011, p. 48). There is no reliable data available which indicate how many of these young people experienced a disability. According to Standard 13 of the National Standards for Out-Of-Home Care, all 15 year olds in care should have a transition from care plan finalised or in the process of being developed. Young people should be engaged in the process of developing their plan and they should ultimately take ownership of the plan (Greenen & Powers, 2007).

Unfortunately, evidence suggests that in 2009 only 36.4% of young people in care were aware that they had some form of transition plan (McDowall, 2009, 2011). Forty percent of young people in the process of transitioning from care did not know where they would be living after leaving care (McDowall, 2009). Two years later, only 31.4% of young people aged 15 to 17 reported having a transition plan in some stage of development (McDowall, 2011). McDowall (2011) reports that of the 48 respondents in the study who reported that they had completed plans, only 50% had a copy of their own document. This is equivalent to 4% of the population surveyed.

The NSW Ombudsman (2004) also found that out of 27 young people with a disability on the brink of leaving care, 19 did not receive any support in relation to transition planning until 6 months, or less, prior to leaving statutory care. The NSW Ombudsman stated that this finding was despite departmental guidelines suggesting that transition planning should commence 12 months prior to the end of the statutory care period. The Ombudsman also highlighted that two of the young people with a disability whose cases were reviewed did not have an allocated caseworker and the Department did not know their whereabouts.

The NSW Ombudsman also stated that transition plans must be relevant to the individual young person who is the subject of the plan and cannot be standardised. The Ombudsman reviewed the case of a

young pregnant woman and found that her transition plan was silent on matters relevant to giving birth and raising a child. According to the Ombudsman, the caseworker had suggested the pregnant young woman was not capable of living independently, not capable of self care and not capable of looking after a new born. Despite the caseworker's beliefs, the Ombudsman found that none of these matters were addressed in her transition plan.

7.3 Transition support network

Transition is, by its very nature, an interagency process (Gil-Kashiwabara et al., 2007; National Collaborative on Workforce and Disability for Youth, 2007; National Council on Disability, 2008; Rous et al., 2007). The United States National Council on Disability (2008) reported that successful transition from care to adulthood is more likely to occur where there is a comprehensive, multisystem transition support network. The network and the plan both need to be multisystemic because it needs to address an array of life domains including gaining and maintaining employment, increasing educational qualifications, accessing and maintaining health care, housing and family challenges (National Collaborative on Workforce and Disability for Youth, 2007; National Council on Disability, 2008).

Typically, transition teams should include the young person, their parent(s) where appropriate, school personnel, medical professionals and representatives from other appropriate agencies such as child protection and disability services (National Council on Disability, 2008). In San Diego transition plans are developed by schools and are specifically designed for young people with a disability aged 18 to 22 (National Council on Disability, 2008). Given that education is such a key determinant of future economic sustainability it is important to emphasise the importance of including school teachers and guidance officers in transition planning processes.

A study conducted by Gil-Kashiwabara et al. (2007) found that transition team members (youth, foster parents, school, child welfare professionals) strongly recognised that a lack of partnership among providers often rendered services ineffective. Young people, irrespective of whether they experience a disability, should be supported and encouraged to participate in their own transition planning process. Key transition decisions should always reflect the vision, goals and best interests of each young person. In other words, young people should have the last say about their transition to adult life.

Another 2007 study conducted in the United States found, among other things, that a lack of interagency involvement in developing a transition plan can be detrimental to the young person who is the subject of the plan (Greenen et al., 2007). In some cases a transition plan was developed by a school while another plan was independently being developed by child protection workers. The plans were not developed in conjunction with each other with the result that neither was a complete plan for the young person involved. Indeed, Greenen et al. (2007) found that those plans developed by the school system had, on average, a 31% participation rate by the relevant child protection caseworker. Moreover, where the school developed plans in the absence of a caseworker, that plan did not include key transition features such as a plan to transition into independent living. Clearly such a plan would be of limited utility in guiding a young person's transition from the child protection system to adult life.

7.4 How to transition effectively

There are many theories as to how young people with a disability should be supported to move from care to independence and adulthood. Greenen and Powers (2007) interviewed young people in care, young people out of care, foster parents, child welfare professionals, educators and other key professionals and found that all of these groups stressed the importance of each young person having a long term and stable relationship with a caring adult so that they can better move into adulthood. They found that such a stable relationship also provided the young person with a stronger sense of self worth.

Kessler (2004) identified four core principles for effective transition from foster care, they are:

1. **Youth development** – preparing young people to meet challenges through a coordinated, progressive series of activities and experiences which help them to become socially, morally, emotionally, physically and cognitively competent.
2. **Collaboration** – process where several agencies and organisations make formal, sustained commitments to work together to accomplish a common mission. This includes functional linkages among child protection systems, schools, medical and mental health services, foster care providers.
3. **Cultural competence** – a state of being where individuals develop by an ongoing process of thinking critically about issues of power and oppression and developing a diversity of beliefs, attitudes and skills that increase their ability to establish trust and communicate with others.

4. **Permanent connections** – the development of positive relationships that are intended to last a life time. Typically this includes biological family, family friends and the wider community. These connections require maintenance and strengthening on an ongoing basis.

Hill and Stenhjem (2005/06) suggest a number of other requirements specifically for young people in care with disability:

1. **Concrete, integrated transition planning** – must contain specific goals, action steps and clear lines of responsibility. Interagency service needs must be integrated into the plan and at a minimum transition plans must include: employment, education, housing, life skills, personal and community engagement, personal and cultural identity, physical and mental health and legal information.
2. **Appointment and training of educational surrogates** – where due to placement instability and disruption educational outcomes are jeopardised, a more consistent approach that includes stable and committed adults to ensure youth received a continuum of educational services relevant for their needs.
3. **Connections with caring adults** – consistent presence or access to at least one adult over time significantly and positively impacts growth and development and it is important that the young person identifies the person(s) the subject of this relationship.

The NSW Ombudsman (2004) found that eligibility for disability services did not ensure a smooth transition. He found that the services the young people were referred to were not equipped to provide longer term or intensive case work. The Ombudsman also found that there were some elements common to more effective planning and that the transition plans reviewed did not reflect these elements. The Ombudsman was of the view that each element not included in a plan was a lost opportunity for the young person who was the subject of the plan. The elements of an effective transition plan identified by the Ombudsman were:

- Engagement with young person through the process;
- Interagency approach to planning;
- Timely engagement of specialist support and/or services prior to leaving care;
- A focus on assessment to determine the young person's skills;
- Leaving care plans that address skills/knowledge deficits identified through assessment;
- Documentation of the leaving care plan with clear reference to goals and strategies, roles and responsibilities; and

- Review dates.

8 Summary

The number of children and young people in care is increasing on an annual basis. Whilst there is no reliable data identifying how many children and young people in care also have a disability experience, research suggest that the prevalence of disability is well above that of the general population.

Children and young people with a disability in care experience more frequent and chronic health issues than other children. Child protection case workers are often ill-equipped to independently identify the health needs of children and young people entering care. This paper has emphasised the importance of professional health screening for all children and young people at the point they enter the statutory care system. Such screening informs case planning and can significantly improve quality of life and developmental outcomes for children and young people in care. This is especially true of children and young people with a disability who often face multiple and challenging health issues. Such children and young people often lack the communication skills to identify that they are in distress. Health screening is therefore of particular benefit to this group.

Similarly, child protection caseworkers are often ill-equipped to identify the disability support needs of children and young people entering care. This report emphasises the importance of child-centred, multi-disciplinary, professional assessments to determine disability support needs and to make recommendations that child protection workers can use in developing a case plan for an individual child or young person.

The report also stresses the importance of providing training to child protection workers about disability issues. A wide body of literature suggests that untrained workers may hold prejudicial attitudes towards children and young people with a disability that can negatively affect protective decision making. Untrained carers and caseworkers can also contribute to increased placement breakdowns and continual placement instability. Placement instability is stressful and detracts from the ability of a child or young person to form bonds with carers that may be possible within a stable placement. Likewise, placement instability can also disrupt social networks at school as it tends to lead to school changes.

Children and young people with disability in care tend to achieve lower academic outcomes than their peers who do not have a care experience. There is little doubt that school changes can lead to a child or young person missing classes and falling behind. There is also little doubt that a change in school also means disruption to friendships and social activities. For a child or young person this can have serious consequences. Like other people, children and young people in care with disability require a certain degree of stability and predictability in order to flourish. Where changes are required, best practice suggests the child or young person is consulted and their opinion forms a key part of the decision making process. Research suggests that additional support and services should be targeted on assisting children and young people to adjust to major changes, or transitions.

This paper also explored a range of issues relating to the transition of children and young people from the statutory care system to adulthood. Research suggests that many children and young people are not a part of the transition planning process or the decisions which will have a major impact on their future lives. These individuals need to be meaningfully engaged in transition planning processes and supported to access the supports and services they will require in adult life. This is especially important for children and young people with a disability who are particularly vulnerable to experiencing adverse outcomes in later life.

Australia has significantly improved the care and protection of children and young people with disability over the last decade. However, it appears we still have some way to go. All Australian jurisdictions need to introduce a common framework to reliably and consistently identify children and young people in care who experience a disability. This could be achieved through a nationally consistent approach to data collection about children and young people with a disability in care, as recommended by the Wallis Group in 1996. This would assist policy makers to identify the scope of need and target resources on ensuring that these children and young people have access to the services and support that they require.

The evidence indicates that with greater collaboration, improved data collection, an increased focus on assessment and early intervention, better worker training and consistent planning practices there is a real opportunity for Australian child protection authorities to significantly improve the quality of life for children and young people with a disability who live in out-of-home care in Australia.

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