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Children with Disabilities using Child and Family Welfare Services

Research Report
January 2014

Gaye Mitchell

About the Author

Dr Gaye Mitchell is a social worker, the Research and Practice Development Officer at OzChild and an Honorary Research Fellow in the Social Work Department at the University of Melbourne. Her research has been undertaken in family support, family preservation, out-of-home care and homelessness services. Her main research focus has been families experiencing intergenerational patterns of poverty, exclusion, disadvantage, and involvement in the child protection and out-of-home care systems.

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Further information: Gaye Mitchell, Ph: (03) 9695 2200. Email: gmitchell@ozchild.org.au

OzChild
Level 3, 150 Albert Rd.,
South Melbourne, Vic, 3205.

www.ozchild.org.au

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Executive Summary

Children with a Disability in Child and Family Welfare

Background

Children and parents with disabilities have always been present amongst those receiving services in child and family welfare. Anecdotally, practitioners in the field know that disability is a contributing factor to the multi-layered complexity they have to tackle in their daily work, if they are to assist the children, carers and families with whom they work to grow, develop and live safely. Despite this, and despite the renewed focus on disability through the new Australian national disability insurance scheme, there is much that we do not know about disability in child and family welfare.

This is the context of the research reported here. The research looked at children with disabilities within child and family welfare services. It explored the extent and nature of disability and what is done and achieved with the children and their carers and families. The need for the research was strengthened when a literature survey found that, while there has been some research into this area, there are many gaps, and that no study could be found which explored these questions across a range of child and family welfare services.

The research project was conducted within OzChild, a child and family welfare agency in the state of Victoria, Australia. OzChild is a non-government agency providing services in the Southern Metropolitan, Gippsland and Barwon South Western Regions of Victoria.[1] Ozchild provides Home Based Care, Kinship Care, Family Services, Disability Services, and a range of educational services and services to schools and students. The educational services which participated in the research included a Community Victorian Certificate of Applied Learning (CVCAL) program which is an alternative to the more academically oriented Victorian Certificate of Education, and Certificates I and II in General Education for Adults (CGEA) taught within OzChild's Registered Training Organisation (RTO).

These services all participated in the research project, which looked at children with a disability in all the listed programs at one point, at the beginning of 2012. Staff filled out a detailed spreadsheet of 42 items on each child with a disability in their caseload. Further, staff were asked to select the most serious case of disability in their case load, and fill out a two page template on the care plan, goals set and achieved, intervention provided, and barriers and challenges faced. The third component of the project involved five case studies, one in each program area, of five children with the most serious disabilities and with whom staff in the program thought they had achieved good outcomes. A cross-program facilitated case discussion elicited data about the child, their disability, intervention with them, and outcomes achieved.

Definition is a fraught matter in the disability arena. Noting definitional inconsistencies and the functional impairment associated with a number of mental illness diagnoses for children, this study adopted the World Health Organisation definition of disability (World Health Organisation, 2012). This definition includes those traditionally seen as disabled, such as those with physical disabilities, including limitations to mobility, those "who are blind or deaf or people with intellectual impairments, and people who experience difficulties in functioning due to a wide range of health conditions such as chronic diseases, severe mental disorders, multiple sclerosis and old age." (World Health Organisation, 2012, p. 3). That is, we included chronic disease and mental illness diagnoses in our definition, if those diagnoses have ongoing effects on the child's functioning. We

[1] Barwon South Western Region was not covered by OzChild at the time the study commenced, so services in that region are not included in this study.

also included all items in the Victorian Disability Act, 2006, which specifies "sensory, physical or neurological impairments or acquired brain injury" or "an intellectual disability or a developmental delay" (Victorian Government, 2006, p. 4), whether they received services under the act or not. We included children with a formal diagnosis of disability and those with a suspected but as yet undiagnosed disability.

During the time of undertaking and completing this report, several reform initiatives in Victoria have been commenced or completed, for example the Cummins Report, DHS structural reform, Services Connect trials, the five year out-of-home care plan and the Shergold Report, the outcomes of which are still to be evaluated. In acknowledging this we also note that some of the findings and recommendations of this report are congruent with these various initiatives but that others identify the need for additional responses or resources.

The project was approved by Anglicare Victoria's Ethics Committee, a Human Research Ethics Committee that functions in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research, 2007.

Findings

The detailed data that emerged from the research formed the basis for numerous findings. Percentages are provided for the sake of comparison, but readers should note that, while 200 children in OzChild were identified as having a disability, the programs contributing to that number, apart from Disability Services, had numbers of less than 50.

- Of the 475 children receiving services in the 6 programs at the snapshot point in 2012, 200 children, or 42%, had a disability. This is a much larger proportion of children with a disability than the general Australian population.
- The percentage of children with a disability ranged from 100% in Disability Services (obviously), to 44% of children in Home Based Care, 32% in the RTO, 29% of children in Family Services and Kinship Care, with CVCAL being the outlier, at 17%.
- 81% of the 200 children received a formal diagnosis, and plans were in place to gain assessment of the majority of informally diagnosed disabilities.
- Half of the children had more than one disability, adding to the level of complexity faced by carers, families and workers.
- An extensive array of disabilities was represented in the 200 children.
- The children struggled to achieve educationally: 4.5% were not attending school, and 28% (56) of the 200 children were achieving well below the expected standard in the grade in which they had been placed.
- Of the 56 children who were significantly underachieving, 20 did not have an aide at school. This figure included 10 young people in the RTO and CVCAL.
- In three programs where the question was explored (Home Based Care, Kinship Care and Family Services), half the children had disabilities that were environmentally based, and therefore theoretically preventable.
- 57% of the 200 children had family members with a disability.

- Intellectual disability was the most common disability in the family members of children with a disability in Home Based Care

- Mental illness was the most common disability in the family members of children with a disability in Kinship Care

- Disabilities associated with Excluded Families – families with long term chronic, serious, and multiple problems across generations – were most common for family members of children with a disability in Family Services.

- ADHD was a common disability, with 14% (29) of the 200 children having this formal diagnosis. ADHD mostly appeared as one of multiple diagnoses. There was co-morbidity in 21 of the 29 cases, and the presentations were complex, with multiple associated disabilities.
- Six of the 55 children in Home Based Care and one of 37 children in Kinship Care had a serious physical disability.
- 48% of children with a disability in Kinship Care and 27% of children with a disability in Home Based Care had disabilities as a result of trauma. An additional 29% of children with a disability in Home Based Care displayed complex and difficult behaviour where the origins of the behaviour were unclear.
- All programs had children whose disabilities stemmed from early trauma.
- 49% of the children with a disability in out-of-home care had experienced placement breakdowns.
- Disability contributed to placement breakdowns for 48% (25) of the 52 children with a disability who had experienced placement breakdowns.
- Where disability had contributed to placement breakdown, the children tended to have a greater number of breakdowns per child.
- Many service gaps and service difficulties were identified in all components of the research. The spreadsheet data on the 200 children did not stem from any questions about gaps and difficulties so that any data extracted is an understatement. Nonetheless, the following needs were identified:

  - additional respite care for 10 placements.

  - additional assistance for 29 children, or 14.5% of the 200 children, to be able to access cultural and recreational activities; however, in that 33% of children with a disability in Home Based Care had such need, the 14.5% overall figure is probably significantly understated.

  - five placements of children with a disability facing placement breakdown because of the disability.

  - more funding for kinship care placements when there is significant additional complexity.

From the 38 case plan templates:

- 104 barriers to goal achievement were identified.

- A number of these applied only to one of the 38 child-situations.

- The three most frequently identified difficulties were: funding that was inadequate to meet the child's needs (five cases); insufficient availability of respite care (four cases); and lack of services for families with complex difficulties (five cases).

- There were 25 service gaps.

- There were 25 identified service difficulties, including 11 case planning difficulties.

- Despite the barriers, workers felt they were able to achieve some important outcomes in 34 of the 38 cases, which speaks to the skill and dedication of the direct practice staff.
- The five case studies provided additional support for findings from other parts of the research. These included detail about processes and resultant difficulties for the children in sufficient depth to facilitate understanding of some of the identified problems. The case studies allowed identification of:

  - serious problems where service systems intersect;

  - multiple barriers to social inclusion and participation for these children;

  - barriers to educational achievement;

  - unequal funding of children with a disability in Kinship Care compared to Foster Care, and between both of these and Permanent Care;

  - the effect of unequal funding in skewing service provision (for example, retaining a child in foster care rather than working towards permanent care).
- The case studies specified some of the processes involved in bringing about change and achieving outcomes, and showed the effects of barriers on individual case workers, carers, families and children.
- The case studies identified further important service system problems. These included:

  - lack of services to birth families where children have been removed from their care, and the negative effect this can have on the children;

  - problems for fathers accessing services;

  - problems arising from the lack of family focus in several adult services.

- Data about the extent of environmental contribution to disability and the relationship between excluded families and disability in the Family Services children

  - provide support for inclusion of functional impairment in the definition of disability;

  - promote consideration of causation of disability;

  - focus attention on macro-level prevention strategies directed to the ill-effects of chronic poverty; and

  - expose the need for multi-level early interventions to prevent environmentally based disabilities.

Recommendations to improve outcomes for children with a disability in child and family welfare services in Victoria

Clarify definition of disability:

- Include functional impairment, regardless of aetiology, in the definition of disability and in eligibility criteria for disability services.

Prevent:

- Prevent disability through macro-level strategies to reduce environmental factors that contribute to the development of disability: poverty, racism, marginalisation, chronic unemployment, homelessness and lack of affordable housing.
- Prevent environmentally based disability at the family level through a more targeted approach to families with multiple and complex needs. The approach must be tailored to their needs and history, providing more flexibly intensive intervention for longer periods of time, embedded in a family centred, ecological, cultural, developmental and competency based approach.
- Prevent placement breakdowns for children with a disability through appropriate levels of support targeted to placements at risk of breakdown.
- Evaluate pilot projects developed collaboratively with the non-government sector to explore a range of innovative program models to find new solutions to the unsolved problems of excluded families – those with chronic, complex and multiple needs.

Construct accessible and holistic adult and child services:

- Build service systems around children and families which respond to the whole child or adult, and which take a family focus.
- Improve access of fathers to services.

Prioritise resource allocation to child and family welfare services:

- Factor into program targets the additional time demands on workers with children with a disability.
- Provide additional resources for professional development in disability for staff in child and family services and alternative education settings.
- Review, enhance and develop approaches to assist children in out-of-home care and family services to achieve at school through partnership between the government and non-government sectors.
- Explore the full range of existing models and innovative proposals in mainstream, alternative and special schools in partnership between government and non-government sectors. Whether using existing or additional funding, develop a bank of effective interventions when children are not achieving at school. A range of models are available, including, but not limited to, additional aides in the classroom, educational workers for children in out-of-home care, and in-home tutoring and support.
- Apply current effective approaches and new initiatives arising from innovation to children with a disability.

- Promote innovation to develop diverse, targeted pilot programs to explore a range of effective interventions to connect children with a disability in child and family welfare services to their communities.
- Ensure availability of respite services for carers of children with very high care needs.
- Ensure children with disabilities in kinship care and permanent care can access the same supplementary funding and resources as children with a disability in foster care; for example, placement establishment, flexi-pack and brokerage funding in all regions, state-wide, with clearly articulated guidelines available equally to all foster and kinship care agencies.
- Provide carer support to permanent carers and increase existing levels of carer support to kinship carers when either are in straightened financial circumstances and face additional financial demands as a result of a child's disability.
- Develop services for birth families with high levels of complexity who have had their children removed from their care and who have conflicted relationships with Child Protection and out-of-home care providers, to maximise constructive relationships between the children and their birth parents, regardless of placement type. Development of such services will require additional funding.

These changes, sufficiently developed and evaluated, would provide the foundation for achieving better outcomes for children with a disability in child and family welfare services.

Children with Disabilities using Child and Family Welfare Services: Detailed Report

Section 1: Introduction, Literature Review and Method

1.1 Introduction

From the beginning of 2012 to the beginning of 2013, OzChild conducted a research project into the nature and extent of disability in children using its services. OzChild staff were concerned to know how many children they were seeing with disability, what sorts of disabilities they were working with, what was working in what they were doing, and what needed changing so that care of and assistance to children with a disability could be the best possible. This report presents the findings of this research and recommendations that arise from it.

1.2 Literature review

A literature review was conducted using the PsycINFO database. Searches were made among additional journal titles of relevance, such as Child Welfare, Australian Social Work and Children Australia, and Australian websites of the Centre for Excellence in Child and Family Welfare, the Association of Children's Welfare Agencies, the Australian Institute of Family Studies (including the National Child Protection Clearing House, and Child, Family and Community sites), the Australian Institute of Health and Welfare and the Australian Bureau of Statistics, all from 2013 back to and including 2000. More than 40 articles and reports were perused.

The review highlighted the problem, not limited to Australia, of definition. Baker notes that the number of disabled 'looked after' children in the UK is unknown, because of such difficulties (Baker, 2011). In the Australian context, Bath, the Create Foundation and Mendes et al. all raise definitional problems (Bath, 2008, p. 10; Create Foundation, 2012, p. 9; Mendes, Snow, & Broadley, 2013, pp. 7-9). Bath and Mendes et al. discuss the question of inclusion or exclusion of mental illness and argue the need for clarification of definitions generally (Bath, 2008, p. 19; Mendes et al., 2013, p. 7). Mendes et al. note that the Disability Services Act in Victoria does not formally include mental illness, while considerable discussion of out-of-home care includes mental illness as the main disability facing children in care (Mendes et al., 2013). Some articles do not provide detail of the definition they are using (Leslie et al., 2003; Lightfoot, Hill, & LaLiberte, 2011). Some use the term 'disability' with precision, using definitions given in legislation that govern provision of services for those with a disability, while also noting that many children have a disability, yet do not receive services (Casanueva, Cross, & Ringeisen, 2008, p. 253). In short, there are significant definitional issues.

An additional definitional question relates to a term often used in both health, mental health and disability literature – that of 'functional impairment' (Üstün & Kennedy, 2009). Although Üstün & Kennedy argue for further work to define and measure functional impairment, it is used in multiple settings to distinguish between diagnoses of different levels of seriousness, and the limitations in various spheres of life that the individual experiences as a result of illness or disability. It is in this sense that the term is used in this paper.

Definition of disability used in this paper

Noting definitional inconsistencies and the functional impairment associated with a number of mental illness diagnoses for children, this study adopts the World Health Organisation (WHO) definition of disability (World Health Organisation, 2012). This definition includes those traditionally seen as disabled, such as those with physical disabilities including limitations to mobility, those "who are blind or deaf or people with intellectual impairments, and people who experience difficulties in functioning due to a wide range of health conditions such as chronic diseases, severe mental disorders, multiple sclerosis and old age."

(World Health Organisation, 2012, p. 3.) That is, we included chronic diseases and mental illness diagnoses in our definition, if those diagnoses have ongoing effects on the child's functioning. We also included all conditions in the Victorian Disability Act, 2006, which specifies "sensory, physical or neurological impairments or acquired brain injury" or "an intellectual disability or a developmental delay" (Victorian Government, 2006, p. 4). We did not limit our focus to only those children receiving services under that Act, because practitioner experience suggested that many children with high needs, and often with a formal diagnosis, do not qualify for services under the Act, but nonetheless required specialist assessment and intervention. We included children with a formal diagnosis of disability and those with a suspected but as yet undiagnosed disability. Formally diagnosed disabilities included only cases/disabilities diagnosed by a qualified practitioner. Only children with disabilities included in the WHO definition or the Act were included in the suspected, but as yet undiagnosed, group. We are not able to make any direct comparison of our findings with research that either does not provide a definition of disability, or where a different definition is used. Definitional difference may account for different findings about the extent of disability in a given population of children.

The literature review revealed that, while there is a considerable body of research about children and disability in the child and family welfare field, there are also gaps. First, we found nothing that addressed the extent and nature of disability across a number of program areas, as this research does. The majority of literature focussed only on a particular part of the service system. For example, Casanueva reported on children in the child protection system (Casanueva et al., 2008). We could not find an Australian equivalent to this study. Many articles, both Australian and international, were concerned solely with children in out-of-home care (Bath, 2008; Chambers, 2010; Delfabbro, Osborn, & Barber, 2005; Hillen, Gafson, Drage, & Conlan, 2012; Leslie et al., 2005; Mendes et al., 2013). Some studies were located within particular sub-sets of out-of-home care, such as home based care (Kerker & Dore, 2006), foster or kinship care (Dunne & Kettler, 2006; Tarren-Sweeney & Hazell, 2006), or residential care (Bath, 2008). There were exceptions. In the UK, 'looked-after children' are sometimes considered as a group (Baker, 2011; Hillen et al., 2012). There is some research in the USA on children with disabilities and substantiated cases of child abuse (Lightfoot et al., 2011). However, we found no Australian exception to the sub-system focus, that is, nothing that researched disability across the whole child and family field.

Additionally, some literature reports research exploring a particular disability, such as mental illness (Burge, 2007; Kerker & Dore, 2006), mental illness and developmental disorders (Hillen et al., 2012), intellectual disability (Slayter & Springer, 2011), or learning disabilities (Taggart, Cousins, & Milner, 2007), rather than the whole spectrum of disability, as this study did.

Existing literature demonstrates considerable levels of disability in child welfare services, but reported levels vary considerably. For example, Casanueva's large study in the USA found that 35.2% of children under 3 years in the child protection system had a disability according to definitions of the Individuals With Disabilities Education Act, but that only 12.7% of these actually received services under the Act (Casanueva et al., 2008, p. 253). A number of similar children might be expected to be found in Victorian Family Services, to which many families with unsubstantiated notifications, one of Casanueva's research groups, are referred. Using a much looser definition, a US study found that "[n]early half (47.9%) of the youths aged 2 to 14 years (N = 3,803) with completed child welfare investigations had clinically significant emotional or behavioral problems." (Burns et al., 2004, p. 960). Burge's study found that 31.7% of permanent wards without access to their biological parents in Ontario had a mental illness (Burge, 2007). Dunne's literature survey found one UK study where 67% of out-of-home care youth had psychiatric disorders, while a US study found 34% of children with significant behavioural problems, and another study suggested that 57% of children entering foster care had developmental problems (Dunne & Kettler, 2006, p. 24). One Australian study found that 61% of children in foster care had mental health or behavioural difficulties (Sawyer, Carbone, Searle, & Robinson, 2007). The Create Foundation Literature review also comments on the variability between studies (Create Foundation, 2012, p. 7). This variation suggests the need for further research to establish whether variations are solely definitional in nature or whether there are fluctuating numbers of children with disabilities in child and family welfare services, the causes of any fluctuation, and what changes might be needed at practice, program and policy level, in the face of resultant findings.

In this article, the Australian Bureau of Statistics report on national prevalence of disability in 2009 is used as the baseline for comparison. The overall prevalence of disability in 2009 was 18.5%, but for children under 4 years the rate was 3.4%, rising to 6.6% for those in the 15-24 year old age group (Australian Bureau of Statistics, 2009).

Another gap is the absence of literature that discusses the role of generalist workers (foster care, kinship

care, family services or teachers) in programs where there are children with a range of disabilities. There is no exploration of the outcomes workers are able to achieve, what works and what does not work in these situations.

These identified gaps in the literature form part of the context of the research and this report. The other context was the desire of OzChild to provide the best possible service to children using its services, or in its care.

1.3 Method

1.3.1 Design

The study involved mixed methods.

Snapshot of all children in OzChild's services at a particular point in time

Data were collected about all children in the participating OzChild programs at one point in time, in early 2012. Each worker in each program was asked to consider their caseload at one point during a three month period, select every child in their caseload who they knew had a formally diagnosed disability, or who they believed had an undiagnosed disability, and provide information on each of these children. Workers knew which children had received specialist assessment and intervention, and also knew the families and children well enough to know if there were behaviours that indicated the presence of undiagnosed disability, or when carers or others involved with the child were concerned that an assessment was needed. Workers were asked to provide data on 42 items, including: age; gender; program; length of time in current Ozchild service; history of previous contact with OzChild services; formally and informally assessed disability, planned process to gain an assessment if informally assessed; name and description of disability; seriousness of disability according to formal and informal diagnosis and worker assessment; effects of disability on child, carer and birth family; education related matters such as year level, year level compared to age, achievement at level, effects of disability on academic achievement, peer relationships and participation in extra-curricular activities; placement and disability related matters such as number of placements, number of placement breakdowns where the disability was the major factor; and history of disability in the family. Five workers were asked to trial the spreadsheet prior to dissemination to all staff, to see if the categories and accompanying notes of explanation were clear to workers. Modifications were made to both as a result of the trial. The researcher met with all programs to discuss the spreadsheet with the direct practitioners, and was available to any direct practitioner who was having difficulty with the spreadsheet. Senior managers, assistant managers and team leaders all strongly supported their staff's participation in the research. All direct practitioners in all participating programs, a total of 52 workers, filled in the spreadsheet.

Care plan templates

Workers were asked to fill out two pages of data on the child in their caseload that they judged to have the most serious disability. Workers provided data on the care plan, intervention, barriers and challenges to providing service or care for the child; on what was done to overcome the barriers; on gaps in case plan and intervention, including gaps in the service system; and on their assessment of the effectiveness of OzChild's intervention in relation to the child's disability.

Case studies

A series of five case studies was conducted. Each program area provided a case study with the exception of the two education programs which provided one case study between them. The case studies provided an in-depth description of the disabilities and intervention. The focus was on the nature and effect of the disability, what could be learnt about successful interventions with children with disabilities at the most serious end of the continuum, and the service gaps within OzChild and the service system. All the selected cases were of children with a disability at the most serious end of the disability continuum according to the experience of that program, but where staff members judged that good assessment and intervention had been provided. Data were collected through a case discussion of three hours, facilitated by the researcher. The session had both research and practice development objectives. It was designed to facilitate the articulation and conceptualisation of practice and sharing of knowledge between staff. Each participating program sent

representatives, and a cross-section of staff, from caseworkers to senior managers, was involved in the sessions.

Analysis and follow up discussions with staff

The data was analysed by the researcher. Excel equations were used to analyse some categories, and qualitative comments were searched for themes, commonalities and differences. Spreadsheet and care plan templates were analysed by program area. The rich data from the case studies were searched for themes, as well as for the individual and particular circumstances of each child in interaction with their family and carer and broader environment.

Finally, findings were discussed extensively with senior managers and program staff, and further data from these meetings were analysed.

1.3.2 Ethics

The research was approved by Anglicare Victoria's Ethics Committee, a Human Research Ethics Committee that functions in accordance with the NHMRC National Statement on Ethical Conduct in Human Research, 2007.

1.3.3 Limitations of the study

While there is no reason to assume that the prevalence of disability seen at Ozchild would be very different in other similar child and family welfare agencies in Victoria, caution does need to be exercised in generalising the results of this study. One reason for caution is the definition of disability. This study has made clear the definition of disability it has employed; however, definitional inconsistencies throughout the field of disability studies contribute to difficulty in comparing findings across studies.

Furthermore, though extensive efforts were made to ensure the reliability of the data collected through consultation with all staff about category meanings and checking categorisation against descriptive material presented, data were collected by fifty-two competent, though different, professionals who inevitably would have introduced a degree of individual variability. Nonetheless, reliance is placed on practitioner evaluations because practioners are seen here as experts in their practice and in understanding those with whom they work.

Section 2: Findings

2.1 Findings from the snapshot data

Several introductory comments are in order with regard to baseline caseload numbers used in this study.

First: the study was a snapshot and some caseloads were not full at the point of the snapshot. This applied to some parts of Disability Services, Kinship Care and Home Based Care.

Second, not all OzChild programs were included. The Volunteer Family Support Program, the Counselling Program, the Youth Focussed School Program and the SHINE Assist Program were all excluded, either because it was felt insufficient data would be available on some clients so that the count would not be reliable, or because staff were only employed on a casual or contract basis which did not include time allocation for research data collection.

Because of these factors, all calculations are based on numbers present at the point of the snapshot, rather than using annual targets, or guesses at average numbers of children in Family Services families. The annual caseloads for the participating programs, in so far as they are known, however, are provided below from the OzChild 2011 Annual report.

Table 1: Annual caseloads of programs participating in the research

Program Name	Annual Caseload (children)
Intensive Therapeutic Family Support	2011 – 65 families. Target set as families, not children.
Families First – 27 Together Again – 12	2011 – 39 families
Kinship Care – Placement and support	138 placements
Home Based Care	163 placements
Disability Services out-of-home care	18 placements including 3 reserved as emergency placements
Disability Services Recreation Program	80 children but only 50 active at any one time. (39 of these are included in the snapshot. There was insufficient data on the remaining 11 children)
Disability Services other programs including Individual Support Packages and respite services	Program numbers vary according to a number of factors. All children under 18 years of age at the snapshot in these programs were included in the research: 13 children.
CVCAL	48
RTO	Impossible to gauge – all ages (under and over 18 years) join the program. There were 25 students under the age of 18 years in the RTO at the point of the snapshot.

2.1.1 Proportion of children with a disability

Snapshot data were collected on 475 children by 52 OzChild caseworkers. The total number of children with a disability at the point of the snapshot was 200, or 42%, of the 475 children.

This rate/percentage is much higher than that of the total population, with 3.4% of children under four years and 6.6% of people 15–24 having a disability (Australian Bureau of Statistics, 2009). The Bureau of Statistics may have been using a stricter definition of disability, though this did not appear to be the case from the descriptions given. These snapshot figures are similar to some findings (Casanueva et al., 2008) and much lower than others (Sawyer et al., 2007). Figures in Table 2, below, show that workers in all OzChild programs have a substantial proportion of people with disabilities in their caseloads, although they often have no specialist training in disability.

Table 2: Prevalence of children with a disability by OzChild program

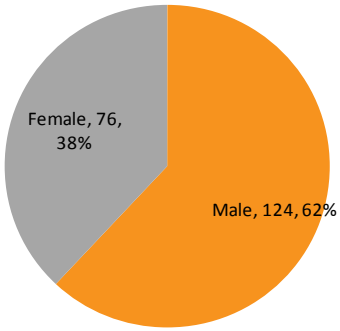
Program	Total N of Children	Total N with Disability	Percent with Disability
Disability Services	70	70	100%
Home Based Care	126	55	44%
Kinship Care	129	37	29%
Family Services	77	22	29%
RTO – CGEA	25	8	32%
CVCAL	48	8	17%
Totals	475	200	42%

The percentage of children with a disability ranged from 100% in OzChild's Disability Services Program, as would be expected, to 17% in its CVCAL Program.[2]

2.1.2 Proportion of male and female children with a disability

Chart 1 shows the number of male and female children with a disability. Reasons for the predominance of male children are not known and this is worthy of further investigation.

Chart 1: Male and female children with a disability - number and percentage (N=200)



2.1.3 Age

Table 3 shows the age distribution and average age of all the children with disability, across all programs.

There is a wide spread of age in Family Services, Kinship Care and Home Based Care. Staff in these three programs are dealing with children from their very early years to late adolescence, needing to be able to support and assist children and carers across the whole age range of childhood.

[2] Percentages are provided for sake of comparison, but readers should note that, while this is appropriate for the 200 children in OzChild who were identified as having a disability, the programs contributing to that number, apart from Disability Services, had numbers of less than 50.

Table 3: Program area by children's age range and mean age

	Years of Age																		Mean
Program	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**Tot**	**Age**
Fam Serv	1	2	1	3	3	1	2		3	2	2		1	1				22	6.9
Kinship	1	2	1	4	2	3	3	2	4	3	3	2	3		1	2	1	37	8.6
H B Care			3	3	5	2	6	4	1	4	8	6	3	5	2	2	1	55	9.6
Disability							2	5	2	4	6	13	6	7	2	14	8	69	13.0
RTO														1	4		3	8	15.7
CVCAL																6	2	8	16.3
Totals	2	4	5	10	10	6	13	11	10	13	19	21	13	14	9	24	15	199	

Clearly, CVCAL, RTO and Disability Services have the highest proportion of older children. RTO and CVCAL are adolescent focussed programs, and Disability Services does not take clients until they are six years of age.

2.1.4 Formally versus informally diagnosed disability

Of the 200 children with a disability, 162, or 81%, had a formal diagnosis.

The proportion of formally compared to informally diagnosed disability varied considerably across programs as shown in Table 4.

Table 4: Rates of formal and informally diagnosed disability by OzChild program area

	Total				
	With	**Formally Diagnosed**		**Informally Diagnosed**	
Program Area	**Disability**	**Number**	**Percent**	**Number**	**Percent**
Disability Services	70	70	100%	0	0%
Home Based Care	55	52	95%	3	5%
Kinship Care	37	22	59%	15	41%
Family Services	22	13	59%	9	41%
RTO – CGEA	8	4	50%	4	50%
CVCAL	8	1	13%	7	88%
Totals	**200**	**162**	**81%**	**38**	**19%**

Since formal diagnosis of a disability is a criterion for entry into OzChild's Disability Services, all children in this program had a formal diagnosis. Home Based Care had the next highest proportion with 52 of 55 children having a formal diagnosis. Kinship Care and Family Services had the next highest proportion. We could hypothesize that family members in Family Services and Kinship Care may be struggling with an understanding of what constitutes disability, which could account for the proportion of children without a formal diagnosis. CVCAL had the lowest proportion.

Workers were asked to report children with informal as well as formal diagnoses of disability. Inevitably, a number of children possessed both a formal and an additional informal diagnosis of disability.

Table 5 indicates that 15% of the 162 children with a formal diagnosis also received an additional informal diagnosis.

Table 5: Percentage of children with an informal diagnosis of disability in addition to their formal diagnosis by OzChild program area

			With an additional	
	Formally Diagnosed		Informally Diagnosis	
Program Area	**Number**	**Percent**	**Number**	**Percent**
Disability Services	70	100%	3	4%
Home Based Care	52	95%	8	15%
Kinship Care	22	59%	8	36%
Family Services	13	59%	3	23%
RTO – CGEA	4	50%	3	75%
CVCAL	1	13%	0	0%
Totals	**162**	**81%**	**25**	**15%**

Chart 2 provides data on the number of children for whom there was no plan for further assessment of informally diagnosed disability, across all programs.

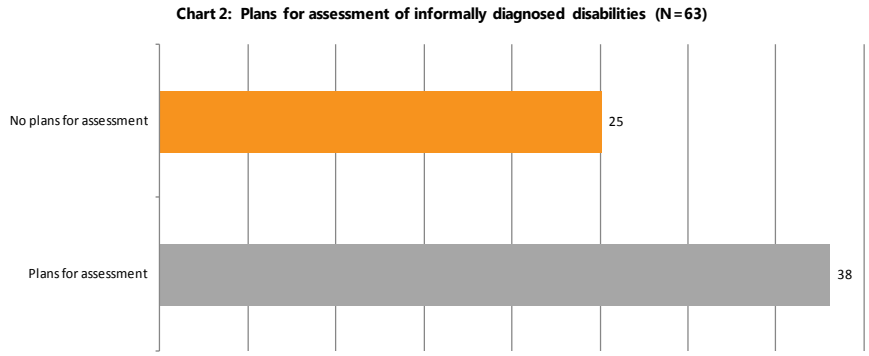
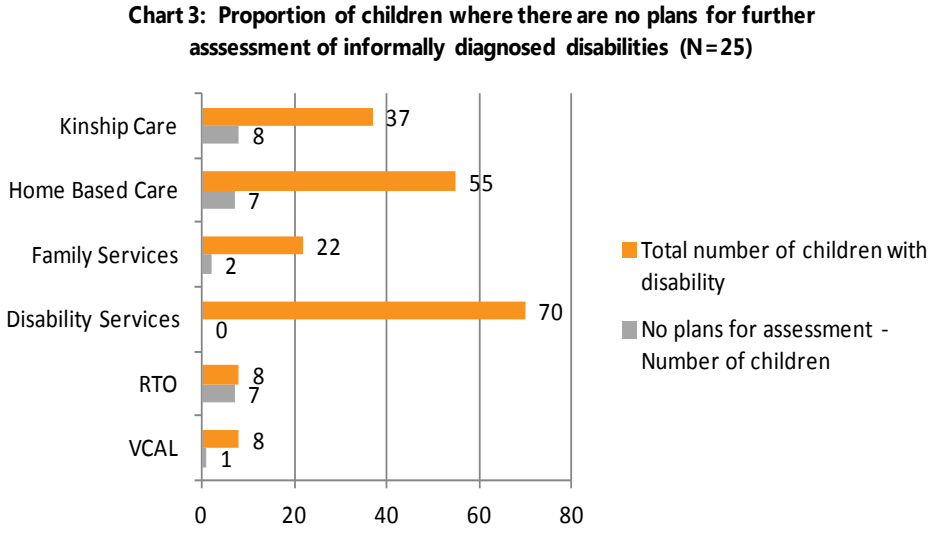


Chart 3 provides the same data, by program area.



There were few plans for assessment in the presence of an undiagnosed disability in the two education programs. Staff in these programs were strongly focussed on achieving educational outcomes. A number of responses and discussion with staff indicated awareness of the need for assessment, but also a sense of being overwhelmed by practical day-to-day imperatives, so that activities directed towards gaining appropriate assessment were not undertaken. Lack of resources for the two groups of students was mentioned by staff in these two programs as being problematic – their perception was that the students were ineligible for some services, and that others needed services that were not available. Staff in the two programs were also largely casually employed or employed to cover contact hours with students, rather than to undertake work of referral and follow up with students in relation to referrals. Staff also mentioned the reluctance of students to follow up their suggestions for seeking help, and that there had been instances where too-active encouragement to seek assistance resulted in increased absence from class. In these cases, the staff opted to 'back off' rather than jeopardise the student's attendance.

Noteworthy for all other programs is the small number of children for whom there were no plans for assessment. However, when the reason for "no plans" was examined, there were only four cases where the lack of plan was questionable. In two of these cases no reason was given for lack of plans for further assessment. In two other cases, one in Kinship Care and one in Home Based Care, both children had complex presentations of disability, and had been assessed and had received diagnoses. Workers appeared to be confused about the contradictory nature of competing diagnoses, and uncertain about what to do in the face of this situation. Further assessment might only provide yet another competing diagnosis.

In the other 12 cases, workers had all considered the need for further assessment. In one case, the Family Services worker was wrestling with the family's lack of engagement with the service. In nine cases, workers had referred the children for specific intervention that had either reduced the symptoms (3 cases) or the therapist was monitoring the need for further assessment (3 cases) or both were occurring (3 cases). In another case, the child's behaviour had settled since coming into care; in a second, a waiting brief was being held, due to the child's age; and in a third, a prior assessment was accepted.

These data suggest staff were very alert to ensuring that the children for whom they were responsible received appropriate assessment and that they received the recommended services.

2.1.5 Single and multiple diagnoses

As shown in Charts 5 and 6, children with formal diagnoses were equally divided between those who had a single diagnosis and those who had multiple diagnoses, but children with informal diagnoses (whether combined with a formal diagnosis or not) were more likely to have a single, rather than multiple, informally diagnosed disabilities. These data likewise suggest that staff were alert to the importance of assessment, shown by the smaller number of children with multiple undiagnosed disabilities.

Chart 4: Formally diagnosed disability - single and multiple diagnoses (N=162)

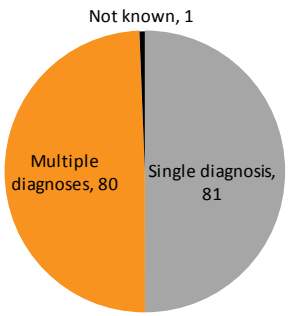
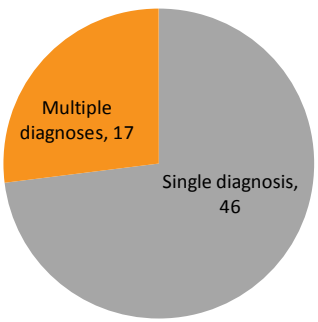


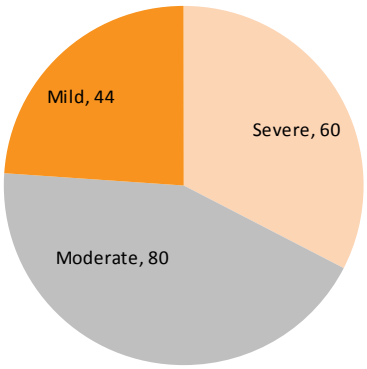
Chart 5: Informally diagnosed disability (N=63)



2.1.6 Worker rating of seriousness of disability

Of the 184 children who received a rating, 60 were rated as having severe disabilities; 80 were rated as moderate; and 44 were rated as mild, as shown in Chart 6.

Chart 6: Worker rating of seriousness of disability (N = 184)



2.1.7 The variety and type of disability

Nothing more dramatically conveys the complexity in the occurrence of disability across an agency caseload than the following table of the variety and type of disability in the children with a formally diagnosed disability. Table 6 shows the extensive array of different types of disability in descending order of frequency, with their occurrence in various programs. The last three rows of the table contain three categories of disability combinations occurring in the data. Some disabilities feature more in Disability Services, but other programs had a share of very serious and limiting disabilities. Additionally, since Disability Services children comprise the largest group in the data, it is not surprising that they have more children in many of the categories. Developmental delay, which includes speech delay, speech delay as a separate category, and Attention Deficit and Hyperactivity Disorder (ADHD) were three areas where Home Based Care and Kinship Care surpassed or equalled the raw numbers of children with these disabilities in Disability Services.

Just to glance down the list of disabilities shows that the disabilities are major ones, with serious consequences for the child, and their family or carer, across the child's life. Some disabilities fall together – for example, autism and intellectual disability, which occurred in nearly half of the children with autism (41 children had autism, 20 of these also had intellectual disability). This is a usual picture for autism. Perhaps the more surprising figure is the number of children diagnosed with autism without an intellectual disability.

Table 6: Number of children by type of formally diagnosed disability within program areas

Type of disability	CVCAL	RTO CGEA	Disability Services	Family Services	Home Based Care	Kinship Care	Total N of Children
Intellectual Disability	0	0	32	1	12	2	47
Autism	0	0	30	3	6	2	41
ADHD	0	1	6	1	16	5	29
Speech Delay or Speech Disorder	0	0	0	3	9	8	20
Autism and Intellectual Disability	0	0	18	0	2	0	20
Combined Complex Physical Disability and Intellectual Disability	0	0	14	0	5	0	19
Cerebral Palsy	0	0	11	0	3	1	15
Global Delay	0	0	3	1	8	0	12
Complex and Severe Physical Disability, including Severe Cerebral Palsy	0	0	10	0	0	0	10
Developmental Delay	0	0	1	3	1	4	9
Epilepsy	0	0	5	0	2	1	8
Oppositional Defiant Disorder (ODD)							
Attachment Disorder	0	0	1	1	3	1	6
Cri Du Chat	0	0	2	3	0	0	5
Asperger's Disorder	1	0	1	1	1	1	5
Post Traumatic Stress Disorder (PTSD)	0	0	0	0	3	2	5
Down Syndrome	0	0	5	0	0	0	5
Learning Disability	0	1	1	0	0	3	5
Anxiety	0	0	1	1	1	1	4
Fragile X	0	0	1	1	1	0	3
Foetal Alcohol Syndrome	0	0	0	0	2	0	2
Problems with Communication	0	0	30	4	12	8	54
Some form of Developmental Delay (combined from 'Developmental Delay', 'Speech Delay or Disorder', or 'Global Delay')	0	0	4	4	16	9	33
Some form of Mental Illness (also included in its specific presentations: ODD, PTSD and Anxiety)	0	2	3	2	9	3	19

While Table 6 provides an overall picture, workers' descriptions conveyed what this might mean for individual children and their carers:

> *One young woman in Disability Services was wheelchair bound, had epilepsy, was non-verbal, incontinent, and was P.E.G fed. She had very high care needs and required a hoist for all transfers. Her single parent provided and managed all her care.*

This was just one example of several children and young people with similar disabilities being cared for in Disability Services, either by parents, or volunteer carers. Home Based Care had one child with a similar level of disability.

Two other children presented a well-known picture for both foster and kinship care:

> *The two were primary aged siblings. One was diagnosed with hearing loss, ADHD, PTSD and high levels of anxiety. This child was easily precipitated into a state of hyper-arousal, had serious problems with self-regulation, was very easily upset and difficult to calm and comfort. The other sibling (in the same placement) had very similar disabilities and symptoms.*

Types of informally diagnosed, or undiagnosed disability, agency-wide and by program

The already dramatic picture of complexity portrayed in the formally diagnosed group of children is further strengthened by consideration of the array of disability in the informally or yet to be formally diagnosed group of children. There were sixty-three children in this group. The range and combination of these disabilities is shown in Table 7. Some children are counted up to three times, if they had multiple disabilities, but the disabilities have been grouped in the subsections of the Table.

Mental illness, ADHD, behavioural difficulties, autism, learning disabilities and developmental delay account for the majority of children in the informally diagnosed group. We can also see that the majority of informal diagnoses fall into the category of environmentally, rather than organically-based disabilities, as will be discussed later in this report. All but eight disabilities appeared to have a strong environmental component. The exceptions were a syndrome associated with the child's mother's epilepsy, and seven cases of autism, including Asperger's syndrome.

Table 7: Number of children by type of informally or undiagnosed disability within program areas

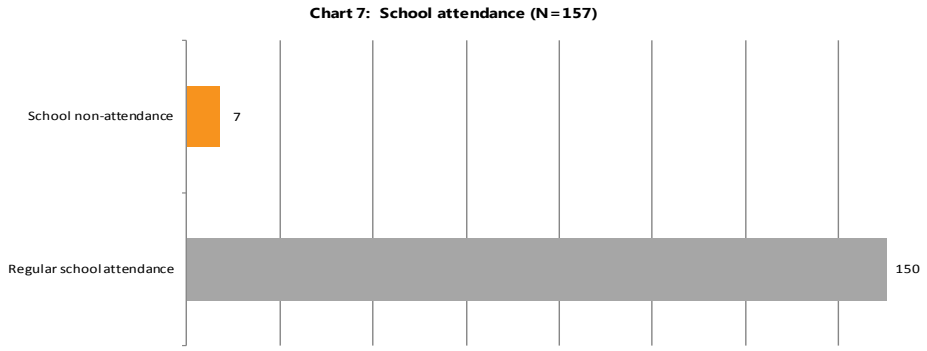
Type of disability	CVCAL	RTO CGEA	Disability Services	Family Services	Home Based Care	Kinship Care	Total N of Children
Mental Illness – excluding attachment disorders	1	5	2	6	3	9	26
- Anxiety				4		5	5
- Anger						3	3
- PTSD or other trauma					1	2	3
- ODD					2	1	3
- Obsessive compulsive Disorder (OCD)					1		1
- Depression		1		1		1	3
- Other		4					4
ADHD (alone)	3			1	1	2	7
ADHD with other symptoms	1			4	1	1	7
- Drug and alcohol	1						1
Family violence	1						1
- Anxiety				3		1	4
- ODD				1			1
- OCD				1			1
- Autism					1	1	2
Behavioural Difficulties				5	1	1	7
- Combined with learning difficulties & ? Autism					1		1
- Combined with emotional difficulties					1	1	2
Attachment Disorder					3	1	4
Autism including Aspergers				1	3	3	7
Learning Disability	2	2		1		3	8
- Dislexia	1						1
Some form of developmental delay						5	5
- Speech Delay or Disorder						1	1
- Global Delay						1	1
- Developmental delay						2	1
- Poor Fine Motor development						1	1
Foetal alcohol syndrome						1	1
Syndrome associated with mother's epilepsy						1	1

2.1.8 Educational performance

The data support previous research that shows that children with a disability face barriers to educational achievement (Australian Bureau of Statistics, 2012; National People with Disabilities and Carer Council, 2009, p. 47) and that children in out-of-home care are less likely to achieve educationally (Wise, Pollock, Mitchell, Argus, & Farquhar, 2010). Young people in OzChild's applied education settings also have a history of lack of educational achievement. Furthermore, data from this study, although presenting only very small numbers, suggest that children in Family Services were struggling to achieve educationally.

School attendance

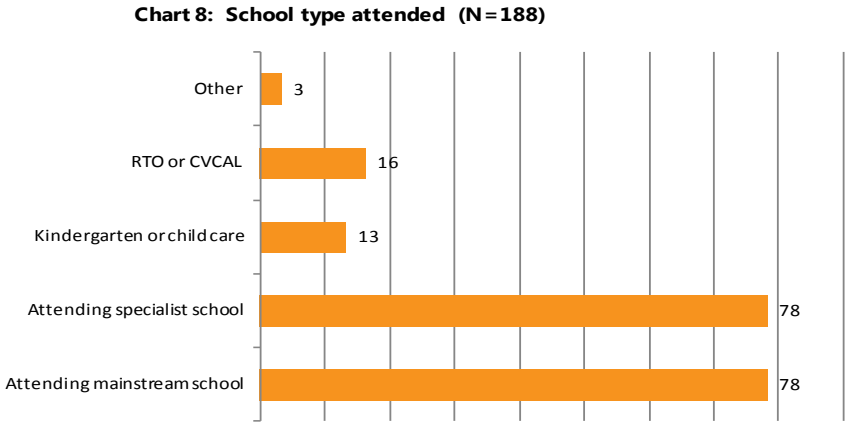
There were data in 157 school-aged children , with 150 regularly attending school and seven not doing so.



The seven who did not attend regularly were all adolescents. Three were enrolled in the CVCAL program, and one was in the RTO program. Of the other three, one was in Disability Services, aged 15 years, with intellectual disability, enrolled at a Special Development School. One was a 14 year old in Home Based Care with intellectual disability and other disabilities, who was failing in mainstream school, but very resistant to attending a Special Development School. The third child was 13 years old, in Year 8, in Kinship Care, with ADHD and serious behaviour difficulties, with assessment showing her performing at a grade 3–4 level.

Type of school attended

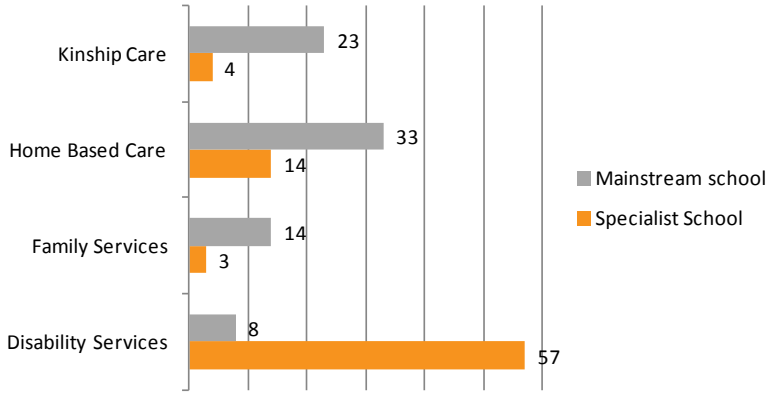
Chart 8 shows the type of school/education attended. It shows that 41% of children attended school in a mainsteam setting. The rest of the children attended special programs, such as CVCAL or enrolment in the RTO's Certificate of General Education for Adults,[3] or a specialist school of some sort: a Special School, a Special Development School, or a school for students with a particular disability such as autism or deafness.



[3] The name of the certificate is perhaps a misnomer, in that the students included in this study were under 18 years of age, and thus not 'adults'.

When this data is analysed by program area, it shows that each program has a proportion of students in a specialist education program. In addition, all CVCAL and RTO students are classified as attending a non-mainstream program, but are not included in Chart 9.

Chart 9: Type of school attended by program area (N=157

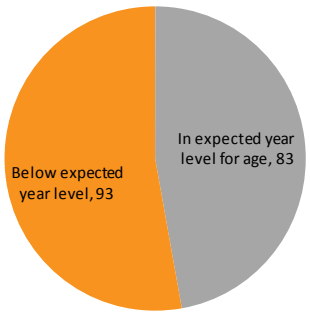


The data suggest that OzChild programs are working to ensure specialist education is provided to children for whom they are responsible.

Children in expected year level for age

There were data on 176 children, of which 83 were in their expected year level, 93 were not.

Chart 10: School achievement (N= 176)



Achievement of children in their current level

A query as to whether a child was "not achieving to the standard expected in the grade level in which they were placed" was used to identify children with disabilities that would impair their ability to achieve at their expected level for their age. Even when using this approach, a quarter, or 56 of the 200 children, were not achieving at school, according to their caseworker's evaluation.

The proportion is actually higher, because for this item, there were data for 156 children. One hundred children were achieving at the year level in which they were placed, 56 were not. Those achieving at their placed level included children with intellectual disabilities attending special schools who were rated by their worker as doing as well as they were capable of doing. (There were 25 children in disability services who were not in their expected year level for age but where the worker rated them as achieving in their current year level.)

Lack of achievement by program area is shown in Chart 11 and Table 8. The data show that there were children in each program area who were not achieving at school.

Chart 11: School aged Children not achieving in the year level in which they were placed (N=56)

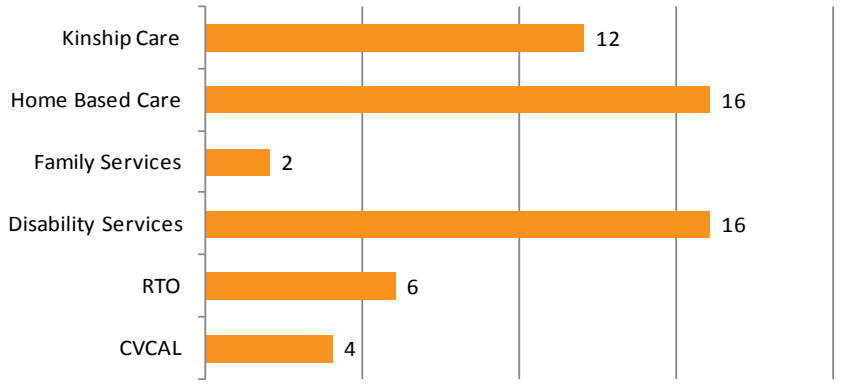


Table 8: School-aged children not achieving in the year level in which they were placed by OzChild program area

Program Area	Total N with Disability	N Not Achieving at Year Level	Percent Not Achieving at Year Level
Disability Services	70	16	23%
Home Based Care	55	16	29%
Kinship Care	37	12	32%
Family Services*	22	2	9%
RTO – CGEA	8	6	75%
CVCAL	8	4	50%
Totals	200	56	28%

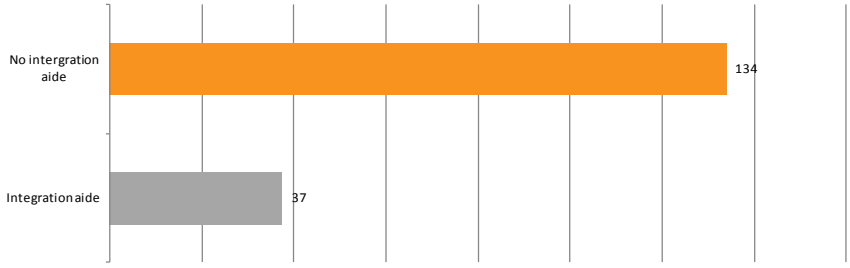
* The figure is low in Family services because eight of the 22 children were preschool age. An additional three children were in Special Schools.

With this large proportion of non-achievement, the question arises of whether the children have sufficient help and support.

Integration Aides

Thirty seven children had an integration aide, 134 did not have an aide.

Chart 12: Number of children with or without an integration aide (N=171)



Sixty children were in a special school of some sort, 46 attended mainstream school (one was paired with another child in his class who had an aide, and there was an application for an aide in progress for another child) and one was being home schooled. Schooling of one child was unknown. Ten children were listed as being in child care or kindergarten. Sixteen of the children attended CVCAL or the RTO.

Chart 13: School setting of children without an aide (N=134)

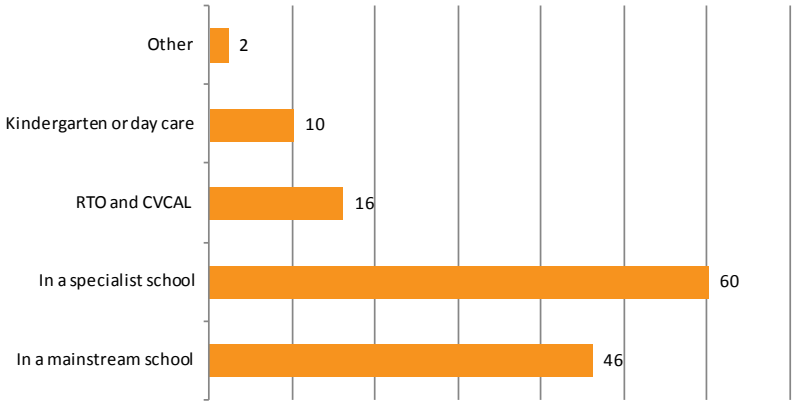


Chart 13 raises some questions. Students in the RTO are not eligible for an aide, but the level of funding may not be adequate to meet the needs of young people with a disability. The same may well be the case for CVCAL, though students in CVCAL would be eligible for aide funding through their base school. This would require careful liaison and linkages between the CVCAL program and the students' base schools. Levels of funding for staff are not high, and students come from a number of schools, creating a large amount of work, if liaison is to be effective.

As might be expected, many of the students without an aide were in specialist school settings for students with a disability. The hope would be that these settings are able to meet the needs of students.

Children not achieving in their year level, with or without the presence of an aide

The data were then examined to see the number and proportion of children who were not achieving in the class in which they were placed, who had, or did not have, an aide. The findings are shown in Table 9.

Table 9: Children not achieving at school by type of school and presence of an aide in OzChild program areas

Program Area	Children not achieving at grade level	Type of School and Presence of an Aide				
		Mainstream School		Special School	Pre-school	Home School
		With an Aide	Without an Aide			
Disability Services	16	4	1	10	0	1
Home Based Care	16	8	3	3	2	0
Kinship Care	12	4	4	2	2	0
Family Services	2	0	2	0	0	0
RTO – CGEA	6*	-	6*	-	-	-
CVCAL	4	-	4	-	-	-
Totals	56	16	20	15	4	1

* These students were ineligible for an aide, despite their need.

There were children in every program who were not achieving and who had no aide. This supports practice knowledge that some children who need an aide are not able to access one and that the lack of aides is significant in the underachievement of some children with a disability. In discussion with staff in all program areas, staff in Family Services and in Home Based Care discussed their experience of trying and failing to get aides for children with disability – particularly those with complex and difficult behaviours.

In our study, at least 10 children were in the position of not achieving and not having an aide, in addition to the 10 students in CVCAL and RTO who were not achieving and had no access to aides – a point of particular concern. As already noted, CVCAL students are eligible for aides, but there are perceived difficulties in providing support without stigmatising the recipient students. CGEA students are not eligible for an aide. Staffing levels in both programs may be insufficient to meet the needs of young people with a disability.

The descriptive data provides a picture of the need for additional support for some students:

In Kinship Care, a primary aged child with a learning disability, attention deficit disorder and reactive attachment disorder, on the face of it, looks unlikely to achieve educationally without some additional assistance. This child wasn't getting any.

Two other teenagers were disengaging from school but were receiving insufficient help in the school setting.

In the CVCAL program, three of the eight young people with a disability were in informal kinship care with serious and complex difficulties and were in need of additional assessment and therapeutic intervention beyond any currently planned.

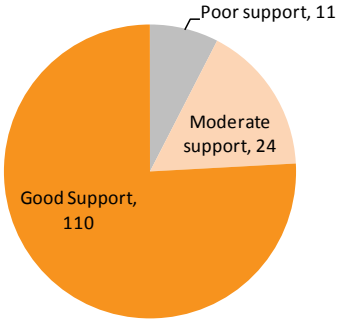
Some children will continue to fail at school unless we find better ways of helping them. This will require increased knowledge and skill in teachers and caseworkers, and funding and development of additional interventions and programs to address their needs.

We also note that 16 children who had an aide were still not achieving at the grade level in which they were placed. This suggests that being allocated an aide is not a panacea, and that more or different approaches are needed to ensure educational achievement for some children.

Worker evaluation of the support received from the child's school

Support received from the school was evaluated by the worker. There were data on 145 children. Eleven children received poor support from their school, 24 received moderate support, and 110 children received good support from their schools.

Chart 14: Worker evaluation of support provided to children from the school (N=145)



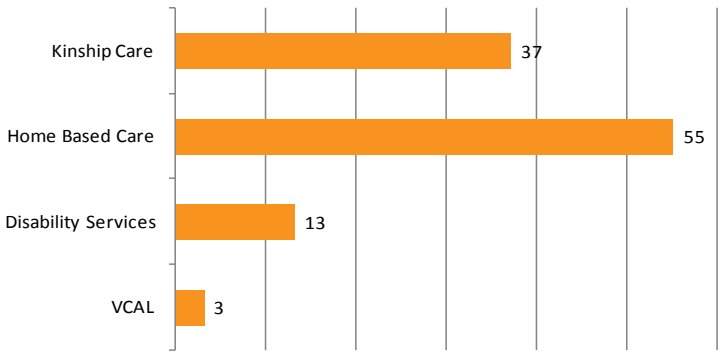
This suggests that the majority of children receive good support from their schools, but that there is room for improvement for 24% of the children.

2.1.9 Children with a disability specifically in out-of-home care

Numbers of children by program with a disability and not living with their birth families

Of the 200 children with a disability, 83 were with their birth parents, and 108 were placed in out-of-home care, on either a voluntary or statutory basis. The data was not filled in for seven RTO students, one CVCAL student and one Disabilities Services child. The children in out-of-home care were distributed among the programs as shown in Chart 15.

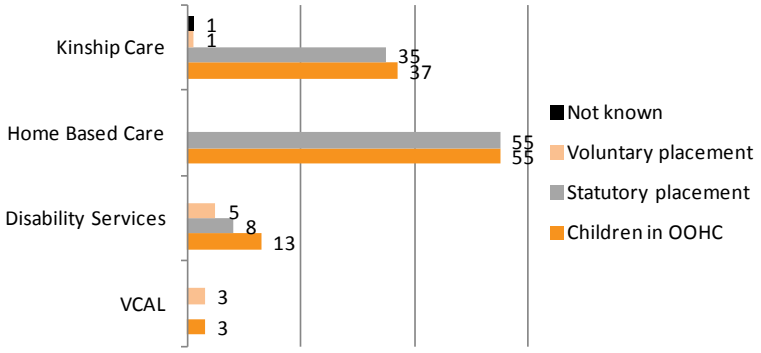
Chart 15: Children in OOHC (N=108)



Type of placement

The division of placement type into voluntary and statutory placement according to program is shown in Chart 16. A large majority of children were in statutory placements, with Disability Services and CVAL having the largest proportion of children in voluntary placement. CVCAL had a surprising proportion of its students with a disability in informal kinship care.

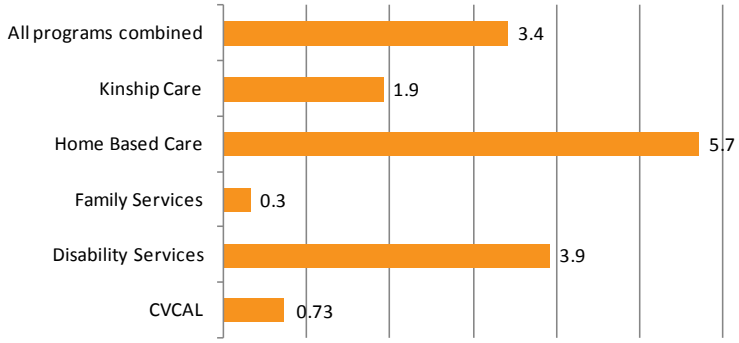
Chart 16: Statutory and voluntary placements of children in OOHC (N=108)



Length of time in care

Children have varying lengths of history of contact with OzChild, as shown in Chart 17.

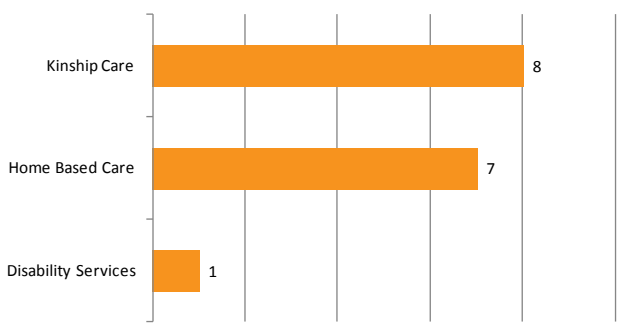
Chart 17: Average length of time with OzChild (years)



Children in out-of-home care programs with an Individual Education Plan

Of the children in out-of-home care, a minority of children who should have had an Individual Education Plan (IEP) did not have one, as shown in Chart 18.

Chart 18: School Age and No IEP (N=16)



In Home Based Care, three of the children were just beginning school as the snapshot was completed. The other four children were all adolescents, three of whom have been in OzChild's care for several years. In Kinship Care, one child without an IEP was just beginning school, five of the young people were adolescent, with two children in primary school.

2.1.10 Pathways into, or origins of, disability, and disability in families of children with a disability

Data on children formally diagnosed in three programs where staff had provided considerable qualitative description were examined to see whether the disability appeared to be organically or environmentally based. As shown earlier, in Table 6, there were different proportions of formal diagnosis in different programs. Home Based Care had the highest rate, with 52 of 57 children with a disability having a formally diagnosed disability. The rates in Kinship Care and Family Services were 22 of 37 children, and 13 of 22 children respectively.

Organic or environmental component of disability in three program areas

In all three program areas, about half of the children with a formally diagnosed disability had an environmental component to their disability, as shown in Table 10. That is, the origins of the disability clearly lay in the child's cultural and socio-economic environment and parent-child or family relationships – a series of dynamics noted in research (E. Emerson, 2007; E. Emerson, Madden, R., Graham, H., Llewellyn, G., Hatton, C., Robertson, J., 2011). Such disabilities included developmental delay without organic cause; mental illness, including oppositional defiant behaviour, post traumatic stress disorder, anxiety and attachment disorder; and learning disability. The researcher categorised disabilities as environmental or organically based according to the clinical diagnoses provided by specialists qualified to make the diagnosis, with supportive evidence from considerable qualitative description provided by staff.

The proportion of environmentally based disabilities increases dramatically if informally diagnosed disability is considered. All but 9 of the 63 children with informally diagnosed disability (25 of whom also had a formally diagnosed disability) had a significant environmental component to their disability.

Table 10: Organic or environmental component of disability in three program areas

Basis of Disability	Home Based Care N=52		Kinship Care N=22		Family Services N=13	
	Number	Percentage	Number	Percentage	Number	Percentage
Organic	12	23%	5	23%	6	46%
Environmental	13	25%	11	50%	4	31%
Mixed	10	19%	0	0%	3	23%
Insufficient Data	17	33%	6	27%	0	0%
Totals	52	100%	22	100%	13	100%

Brief descriptions of the children in three of the programs show the difference between the organically and environmentally based disabilities.

Home Based Care – organically based

- Three siblings, one with mild cerebral palsy, one with severe language disorder and borderline autism and one with intellectual disability. In this family two children had mild disabilities, and a third had autism – three distinct disabilities in one family.
- A child with severe cerebral palsy, spastic quadriplegia, wheelchair bound and dependant on others for all mobility, non-verbal and with epilepsy.
- A child with severe, physically-based failure to thrive requiring P.E.G. feeding, and with developmental delay.
- A deaf child and another child with Type One diabetes.
- A child with intellectual disability and another with intellectual disability and a chromosomal disorder.
- A child with severe liver disease resulting in vision impairment, developmental delay, mild intellectual

disability, epilepsy and some severe behavioural difficulties, including poor impulse control, absconding, defiance, and aggression/violence.
- A child with spina bifida and epilepsy.
- A child with a physical disorder with severe effects on organ function.

Home Based Care – environmentally based

- Two children with ADHD, but with symptoms such as hyper-arousal, anxiety, and with known histories of trauma.
- Two siblings with speech delays and histories of trauma.
- Five children with post traumatic stress disorder, two of whom also had attachment disorder.
- Two children with ADHD and oppositional defiant disorder.
- One child with developmental delay.
- One child with complex mental health presentation, including self-harm and delusions (since disappeared), and aggression.

Home Based Care – mixed contributions to disability

- Two children with foetal alcohol syndrome, one of whom also had cerebral palsy, and the other Fragile X Syndrome.
- A child with reactive depressive illness and attachment disorder, but where a mother and two siblings have mental illness.
- Two children with intellectual disability and ADHD, but where a parent and siblings all have intellectual disability; a third child with intellectual disability, and being assessed as borderline autism spectrum disorder; and a fourth child with intellectual disability, but also with oppositional defiant disorder; and a fifth with intellectual disability, dythmic depressive illness and ADHD (but in a context of early experiences of trauma).
- A child with intellectual disability with some behavioural difficulties that seemed tied to the child's pre-care situation.
- A child with mild Tourettes Syndrome, but also with attachment disorder, ADHD and oppositional defiant disorder.

Some organically-based disabilities present with severe behavioural disorders and difficulties, which present difficulties for assessment. For example:

> *The child described earlier with severe liver disease resulting [in] physical, intellectual, developmental and medical difficulties also presented with severe behavioural problems.*

Further, some environmentally-induced disabilities are of a nature that causes great distress for the child, their carers and anyone who has to relate to the child. For example:

> *One child was diagnosed with reactive attachment disorder, generalised anxiety and post traumatic stress disorder. The child's presentation was characterised by chronic anxiety, a fear of change, rigidity of thought, limited empathy and poor social skills. Exposed to chronic domestic violence in the first three years of life, the child exhibited behaviours such as kicking, biting, throwing objects, and being destructive in relation to personal property*.

Kinship Care – organically based

- One child with cerebral palsy, intellectual disability and epilepsy. This child had two siblings with disabilities that were probably environmentally induced: ADHD in one case and oppositional defiant disorder with violent tendencies, anger management issues and learning difficulties, in the other.
- Two siblings, both with autism and both receiving specialist educational services for children with autism.
- One child with Asperger's Syndrome.
- One child with a specific physical disorder, with associated growth and learning difficulties.

Kinship Care – environmentally based

- Speech delay in a four year old.
- Two teenage siblings, the younger with ADHD, very evident at home, and also with effects on peer relationships at school, although achieving academically; the older with ADHD, oppositional defiant disorder, dyslexia and dyspraxia, and difficulties with anger management – rooted in experiences of early trauma. These two children also had a sibling with cerebral palsy, intellectual disability and epilepsy, listed above in the organically-based category.
- A primary aged child with severe language and speech disorder and reactive attachment disorder. The child had limited ability to communicate and to understand and had had several foster care placement breakdowns and one kinship care breakdown because of these difficulties.
- A primary aged child with some features of foetal alcohol syndrome, who demonstrated severe/ challenging behaviours in some situations including running away, hitting people, screaming, hiding. The child has an intellectual impairment and attention difficulties.
- A primary aged child with learning disability, ADHD and reactive attachment disorder.
- A primary aged child with impaired receptive language and language difficulties, believed to be due to lack of environmental stimuli in early years.
- A teenager with ADHD, but with aggressive behaviours, a number of expulsions from school, and bans from extra-curricular activity because of challenging behaviours.
- A primary aged child with PTSD, including high levels of anxiety, anger, and guilt.
- A child with speech disorder and suspected ADHD, and a sibling with generalised anxiety disorder.

The data was insufficient to form an opinion in 6 of the 22 cases.

Family Services – organically and environmentally based

- Six (6 of 13) had organically based disability (cri du chat for three children, autism, autism and Fragile X, and Aspergers Syndrome accounting for the other three children).
- Four (4 of 13) had environmentally induced disability (oppositional conduct disorder, reactive attachment disorder, failure to thrive and developmental delay, ADHD).
- Three (3 of 13) had a mixture of environmentally induced and organically based disability (intellectual disability and autism; ADHD, obsessive compulsive disorder and autism; and anxiety, diabetes and a third genetic disorder).

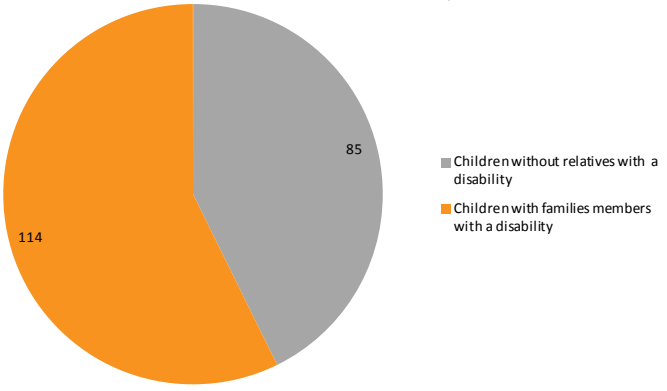
All children in the nine excluded families (those with multiple, chronic, entrenched, intractable problems over two to three generations) had either environmentally induced disability (9 children) or a mixture of environmentally induced and organically based disability (2 children). However, six of these children had informally rather than formally diagnosed disability.

Our conclusions and recommendations section will take up the implications of these findings.

Disability in family members

A large proportion of children with a disability also had family members with a disability. As shown in Chart 19, 114 of the 200 children with a disability, or 57% of the children, had other family members who also had a disability.

Chart 19: Children with relatives with a disability as a proportion of children with a disability (N = 200)



Data from specific program areas are shown below in Tables 11 and 12.

Table 11: Number and percentage of children with a family member with a disability

Program	Children with a disability	Children with a family member with a disability	
		Number	Percent
CVCAL	8	1	
RTO	8	3	
Disability Services	70	26	37%
Family Services	22	19	86%
Kinship Care	37	26	70%
HBC	55	40	72%
Totals	**200**	**114**	**57%**

Table 12: Number and percentage of types of family relationships and disability

Program	Children with a disability	Children with parents with a disability		Children with only siblings with a disability	
		Number	Percent	Number	Percent
CVCAL	8	1			
RTO	8	2		1	
Disability Services	70	15	21%	11	15%
Family Services	22	18	81%	1	4%
Kinship Care	37	15	37%	11*	29%
HBC	55	23	42%	17	31%
Totals	**200**	**73**	**36%**	**41**	**20%**

* One child in kinship had a family member with a disability, but the nature of the disability or family relationship was uknown.

There was considerable complexity in many families and some points of interest:

- Thirty-two families with 43 children had multiple disabilities in two generations in the families.
- Thirty children had one parent with a disability.
- Twenty-five families with 39 children had more than one child with a disability.
- One family had three adopted children, all with a disability.

An interesting relationship emerged between disability and a particular group of Family Services clients called excluded families (Tierney, 1976; Mitchell & Campbell, 2011). Excluded families are those with multiple, entrenched, intractable, chronic and serious problems across multiple generations in one family (Mitchell & Campbell, 2011, p. 427). Mitchell and Campbell provide criteria for assessment of excluded families, and these and the qualitative description provided by staff enabled the researcher to distinguish between excluded and non-excluded families in the Family Services cohort. The vast majority of families in Family Services in this study (15 of 17 families) had multiple famsily members with a disability covering two generations. This was a much higher proportion than in the other programs. Nine of the 15 families appeared to be excluded families. The nine excluded families had eleven children in this study, or half the Family Services cohort of children. Of these children, all but one had environmentally based disabilities. This one child had autism and intellectual disability. For all the other children in the excluded families, ten in all, multiple diagnoses were common and included mental illness diagnoses such as oppositional defiant disorder, anxiety, depression, and effects of trauma from family violence. There was one diagnosis of serious developmental delay and one of ADHD, and the caseworker located the child's difficulties in the family-environment context in this latter case. By comparison, children in the five non-excluded families with intergenerational disability had different, largely organic, types of disability: for example, genetic or physical disorder.

In fact, in all three programs where the origins of disability were examined closely – Home Based Care, Kinship Care and Family Services – children with both organically and environmentally based disabilities were being cared for. The different origins and pathways in some instances called for different responses, and in others needed identical intervention, once the disability was established. Some of the disabilities were of a very serious nature, presenting substantial challenges for the child and their carer, as well as for school and social settings.

Further, there were a substantial number of children in out-of-home care whose pre-care environments had caused or significantly contributed to serious levels of ongoing disability. In Family Services, at least half the children had a component of environmentally induced disability, and this figure rose considerably when the informally diagnosed disabilities were included – especially in the excluded family group.

Nature of disabilities in family members

There was a difference in the nature of disabilities of family members in different program areas. Different kinds of disabilities were present in family members in different programs.

- Excluded families, with their environmentally based disabilities, were the predominant group in the Family Services cohort.
- In Home Based Care, intellectual disability featured most commonly as the disability in other family members. In seven of the 18 families, the family member had intellectual disability. This was also the case in an eighth family, but there were also characteristics suggestive of exclusion. Two other families with disability in family members and the child seemed to fit the excluded family category. We would expect that the number of excluded families among birth families would be much higher than these figures suggest. That this did not emerge may be a function of workers in Home Based Care not being funded to work closely with birth families and thus having less knowledge of them. Nor did the study specifically ask about dimensions which would identify excluded families. The evaluations made here were made on the basis of the data that was presented in relation to other questions and categories.
- In Kinship Care the most frequently occurring disability was mental illness in the parents. There were 7 families where one or both parents had mental illness. One of these families had two children counted in the spreadsheet.

    - Three of these seven families had both parents with a mental illness.
    - Two families had mothers with mental illness and fathers who were alcoholics.
    - Two families had just one parent with a mental illness.

This finding has face validity. If a parent becomes severely affected by mental illness or substance addiction, then their kin might step in to care for the children.

2.1.11 The question of ADHD

Formally diagnosed ADHD typically presented with a range of other formal diagnoses. This was the case for 21 of the 29 children with ADHD. The disabilities co-existing with ADHD are shown in Table 13, which shows the complexity and variety of presentation.

There were some groupings, but the presentation was complex. In four children, ADHD and intellectual disability were present. Seven children had ADHD and oppositional defiant disorder (although only three of these were diagnosed with only oppositional defiant disorder and ADHD). Another seven presented with ADHD and autism spectrum disorders (although two of these also had oppositional defiant disorder and are counted also in the previous grouping). ADHD had, in reality, a very complex presentation, with 14 different combinations of diagnoses for the 21 children with co-morbid presentations of ADHD.

This complexity of presentation may indicate problems with conceptualisation and diagnosis of ADHD that would obviously present ramifications for intervention.

Table 13: ADHD and co-morbid presentations

ADHD presentation	CVCAL	RTO	Disability Services	Family Services	Home Based Care	Kinship Care	Totals
ADHD alone		1		1	4	2	8
Autism Spectrum Disorders and ADHD			1		1		2
Anxiety and ADHD			1				1
Autism Spectrum Disorders, Oppositional Defiant Disorder and ADHD			2				2
Intellectual disability and ADHD			1	2			3
Intellectual Disability Autism Spectrum Disorders and ADHD			1				1
Attachment Disorder and ADHD				1			1
Oppositional Defiant Disorder and ADHD					3		3
Developmental delay and ADHD					1		1
Developmental delay, Autism and ADHD					2		2
Oppositional Defiant Disorder, Attachment Disorder and ADHD					1		1
Oppositional Defiant Disorder, speech delay and ADHD						1	1
Hearing Loss and ADHD					1		1
Learning disability and ADHD						1	1
Suspected mental illness and ADHD						1	1
Totals	**0**	**1**	**6**	**2**	**15**	**5**	**29**

To a slightly lesser extent, the same picture emerges for the informally diagnosed or suspected disability group of children, as shown in Table 14. The combined data from both the formally and informally diagnosed groups suggest that complexity and perhaps confusion is still present in relation to ADHD.

Table 14: ADHD and associated disabilities in the informally diagnosed group.

ADHD presentation	CVCAL	RTO	Disability Services	Family Services	Home Based Care	Kinship Care	Totals
ADHD on its own	3					2	5
ADHD and substance abuse	1						1
ADHD and autism spectrum disorders				1	1	1*	3
ADHD and range of mental health diagnoses (anxiety, oppositional defiant disorder, obsessive compulsive disorder)		1		5			6
ADHD and intellectual disability				1			1
Totals	**4**	**1**		**7**	**1**	**3**	**16**

* Occurring concurrently with anxiety

2.1.12 The seriousness of disability, identified service gaps and difficulties and effects of disability on placement stability

The following analysis is based on workers' comments recorded in the spreadsheet for all 200 children. Comments related to the disability, its level of seriousness, and its effects on the carer, the child, school achievement, the child's peer relationships, participation in extra-curricular activities, previous placement breakdowns, and on the current placement. The most interesting findings related to the severity of the disability, service gaps and difficulties (despite data collection questions not exploring these questions directly), and effects on placement stability.

Seriousness of disability and service gaps for CVCAL and the out-of-home care programs (including children within Disability Services' out-of-home care program)

Types of disability have been explored for all programs in previous sections. The following analysis examines selected programs to highlight some interesting similarities and differences, and to avoid repetition of findings (for example, Section 1.10.1, discussion of Family Services). The programs discussed below are the three out-of-home care programs in Disability Services, Home Based Care and Kinship Care, and the CVCAL program.

Seriousness and type of disability

In CVCAL, eight students were identified as having a disability. Four had ADHD, one was diagnosed with mental health issues, one with dyslexia, one with a learning disability and one with Asperger's Syndrome. However, the picture was more complex than this, with three of the young people also being in informal kinship care, two having extremely complex family situations in addition to ADHD, and the young person with mental health issues having suffered significant grief and loss, which fundamentally affected her capacity to learn and achieve at school.

In Disability Services, 13 children were in out-of-home care, and eight of these had severe physical disability. All of the eight were non-verbal, nearly all were incontinent, two were non-ambulant, one was P.E.G. fed and three were at risk of placement breakdown because of the extremely high needs of the children.
Three of the thirteen children had mental health issues, were affected by trauma, or had diagnosed attachment disorder.

In HBC there was a much greater range of severity of disability, compared to the children in Disability Services. Six of the 55 children with disability had severe physical disabilities. Each of the six had a different disability, requiring different support from the case worker and presenting different challenges to the carers.

One child had multiple disabilities of an extreme nature, had no movement, was non-verbal with hearing and vision impairments, as well as being P.E.G. fed. A second child also required P.E.G. feeding. The disabilities of all six were as severe in their consequences for the children and their carers as many of the children in Disability Services OOHC. In all cases the carers were doing an excellent job, and there were no obviously-apparent unmet needs. (We note this is a deduction from the data presented, which did not ask workers to identify unmet needs). It also should be noted that care of these children, as with the care of the children in Disability Services, required very high levels of moment-to-moment, day-by-day commitment, time and energy from the carers.

The largest group of children with a disability in HBC was a group of 31 children with complex and difficult behaviours.

In half of these cases, or in fifteen children, the origins of the behaviours were located in experience of trauma. Ten of these children had made excellent progress since coming into care. Here is one example of a child with symptoms described by his worker as 'mild':

> *A primary-aged child had symptoms of ADHD, but workers wondered whether the behaviours were more related to experiences of early trauma. The child displayed oppositional and defiant behaviour, especially when unable to get their own way. The child was lagging behind academically by about 6 months. The child would only attempt work if they thought they could succeed, and then gloated over peers when this was the case. The child had problems with empathy and humour, which were an additional barrier to peer relationships. Problems with concentration formed a barrier to extra-curricular activities, such as team sports.*

A more extreme example is presented by two siblings placed together:

> *A primary aged child was diagnosed with hearing loss and with ADHD and PTSD, high levels of anxiety and [was] easily precipitated into a state of hyper-arousal. The child had serious problems with self-regulation, was very easily upset, and difficult to calm and comfort. The child's older sibling also had ADHD and PSTD, was emotionally labile and presented difficult behaviours such as lying, poor socialisation behaviours, and was very demanding.*

Ten of the children, including the first example above, seemed to be doing very well with their carers, and their difficult behaviours and levels of distress were diminishing. Five others, including the children in the second example, were making progress but the carers faced moment-by-moment challenges and demands from the children.

A further 16 children displayed complex behaviours but the provided diagnoses and the worker experience were not able to locate the difficulties in previous experiences of trauma.

For example:

> *One child's father had a history of mental illness (schizophrenia and depression) and the child had had delusional episodes. This child had emotional and behavioural issues, was defiant, had problems emotional self-regulation, had problems sleeping, was a binge eater, and threatened self-harm. The child was achieving at school, though was having trouble with peers. The contribution of trauma and early experiences with the father were unclear.*

For eight children, the behaviours could be related specifically to their particular disability, sometimes in combination with their stage of development. For example:

> *A teenage child was born drug addicted with significant liver disease, intellectual disability, vision impairment and epilepsy. This child had poor impulse control and was beginning some absconding and defiant behaviours.*

None of the 37 children with a disability in Kinship Care presented with physical disabilities as severe as the most severely disabled children in Disability Services or Home Based Care. Nonetheless, Kinship Care staff were assisting children with a variety of disabilities across a range of severity. The Kinship Care group was dominated by a group of 18 children whose disability was the result of trauma or other family of origin experiences. Eight of these children displayed significant behavioural difficulties.

For example:

> *One child in primary school demonstrated severe challenging behaviours in some situations including running away, hitting people, screaming and hiding. The child had an intellectual impairment and attention difficulties. The child sought security and stability and became quite distressed when an established routine was upset.*
>
> *Another child could be quite happily playing at child care, but when they became upset, would destroy other children's toys, push and shove, swear a lot, and had lash out at staff. Some parents withdrew their child from the child care centre because of this child's behaviour.*

Extent and nature of unmet needs

In CVCAL, nearly half of the young people had need for further individual and family assessment and intervention, and all of the eight needed extra assessment and intervention to achieve at school.

Disability Services also experienced gaps in services, the most frequent being the absence of support for involving children with severe disability in extra-curricular, recreational or cultural activities, and lack of respite care, especially for children with very high needs. (Eight children and young people needed extra assistance if they were ever to be involved in extra-curricular activities, and four families were in need of additional respite care).

In HBC, compared to Disability Services, there was a different range of needs, or gaps in assisting these children achieve their highest level of capability. The data suggested that 12 of 55 placements stood in need of some additional support and assistance – either for the child directly, or for the carers.

- Seven carers needed respite care, or additional help to meet the needs of the child while also attending to other family needs.
- Four children needed an aide in school in view of their lack of achievement, problems with concentration, or need for one-to-one attention.
- Eighteen children needed some additional help or different activities, if they were to participate in extra-curricular activities. Eight children had severe problems with concentration which meant they were unable to take part in mainstream sporting or cultural activities. Five young people were not able to participate in mainstream activities because of their complex and difficult behaviours including oppositional defiant disorder, post traumatic stress disorder, anxiety, fear of failure, and experiences of being bullied. Three children needed activities designed for children with very severe physical disability. One needed some sort of activity suitable for a young person with very fixed and rigid thinking. One young person lacked confidence to such an extent that they were unable to join in.
- One parent felt she needed additional education about the child's needs and how to support educational achievement in the home environment.

It is noted, however, that 27 of 55 placements of children with a range of disabilities were doing very well in placement and did not seem to have additional or unmet needs.

A variety of unmet needs were also identified in the Kinship Care group, but with the largest area being lack of support for children who were failing at school. This was the case for 13 of the 37 children. For example:

> *Two young people in early secondary school were of great concern. Both were failing at school and were on reduced school hours of attendance, both having faced multiple suspensions and expulsions. One had an aide, and one did not. One of the placements was under threat of breakdown because of the young person's aggressive behaviour.*

In seven of these cases, the need for an aide seemed unequivocal. For example:

> *A primary school-aged child had a learning disability, attention deficit disorder and reactive attachment disorder. This child was failing to achieve at school and did not receive any additional support or assistance. Another young person was in a very similar position.*

The additional four children were failing at school, despite either attending a special school, or having an aide in a mainstream school. They needed additional or alternative assistance.

Children in the Kinship Care group had a range of other unmet needs. These included: anger management for the child and parent education for the carer; an independent peer-carer for a physically and intellectually disabled young person to foster age-appropriate and safe recreational experiences; additional help to find pathways to employment and training for a late secondary school student with learning disabilities; clarity of assessment given disputes between specialists; an aide to assist at least two children in accessing recreational or cultural participation, given their behavioural difficulties; assistance to help financially constrained carers pay for Occupational Therapy and Speech Therapy (identified in two cases); and problems with the interface between out-of-home care and Disability Services.

In Kinship Care, and avoiding double counting, 16 young people and/or their carers were identified as having additional and not fully met needs. No obvious unmet needs were identified for 17 children and their carers.

Effects of disability on placement breakdown

In addition to the information gleaned from workers' descriptive comments, information about the number of placement breakdowns and whether the child's disability had contributed to them were specifically sought. The information is presented in Table 15. In addition to these figures, seven living situations of children, sometimes in care, sometimes with their parents, were identified by workers as being at risk of breakdown, or suffering considerable stress, because of insufficient support.

Table 15: Number of placement breakdowns by program area, and contribution of disability to placement breakdown

Program Area	Number of children with placement breakdowns	Number of placement breakdowns	Number of breakdowns where disability was a contributing factor	Number of children where disability was a contribution factor
Disability Services	14	22*	14*	5
Home Based Care	27	61	44	16
Kinship Care	11	22*	11*	4
Totals	**52**	**101**	**69**	**25**

* Two entries referred to 'several' placement breakdowns, which are estimated here as four.

In the three out-of-home placement programs, a total of 105 children were identified as having a disability. Of these, 52 had experienced placement breakdown. That is, 49% of the 105 children with a disability in out-of-home care had experienced placement breakdown. Of these 52 children, 25, or nearly half of them, had placement breakdowns where their disability was a contributing factor.

Further, 52 children had 101 placement breakdowns, or 1.9 breakdowns per child, and the 25 children where disability was a contributing factor had 69 placement breakdowns, or an average of 2.7 breakdowns per child. That is, where disability contributed to placement breakdown, there tended to be a greater number of placement breakdowns. Caution needs to be exercised in relation to this conclusion, because of the small number of children, the effect on the data of a couple children with high numbers of placement breakdowns, and two cases where the worker referred to 'several' placement breakdowns.

When the reasons for breakdowns were examined, it emerged that in the vast majority of cases, the children's disabilities resulted in seriously challenging behaviours which a number of carers had difficulty managing. These included diagnoses of ADHD, oppositional defiant disorder, autism spectrum disorders, attachment disorder, and severe delay, sometimes in combination in the one child. For example, eight of the 25 children had an autism spectrum disorder, which in four cases was co-morbid with ADHD and in two cases also with oppositional defiant disorder, or developmental delay. In one case a physically disabled child was diagnosed also with autism. Eight of the 25 children (four have already been counted in the discussion of autism spectrum disorders) had ADHD. Five children had some form of physical disability, and in two of these five

cases, intellectual disability and autism spectrum disorders were also present.

Summary

1. Differences between Disability Services out-of-home care, Home Based Care and Kinship Care

- Disability services had a much higher proportion of children and young people with severe physical disabilities.
- Four of the eight placements were in need of additional support: respite for a carer with nurse training, respite care and, in two cases, additional in-home support given the high care needs of the children.
- Six children in Home Based Care also had severe physical disability, equivalent to some of the severe disabilities in Disability Services.
- One child in Kinship Care had a severe physical disability.
- A proportion of children in all three programs had experienced significant trauma, or had diagnosed attachment disorders. The proportion was lower in Disability Services than the other two programs. Home Based Care had about 40% of its children with trauma experiences or attachment disorder or the child displayed complex and challenging behaviours which might or might not result from these. Kinship Care had a higher proportion (a little under one half of the children), but this count relies on some assumptions about links between the described behaviours and experiences of trauma, other family of origin experiences, or attachment disorder.
- Effects of inequities in funding between kinship care and foster care emerge in the spreadsheet and case study data. Children with complex disabilities or behaviours received different levels of funding depending on the program in which they were placed, and regardless of efforts of case workers to gain supplementary funding. A number of kinship placements were struggling to find sufficient resources to support placements because of this reality.
- We note again that questions on the spreadsheet did not ask specifically about unmet needs, so caution must be exercised when interpreting data that did not mention unmet needs. With this qualification, the data suggested that all programs had placements where the children had significant needs, but comments indicated that the carers were providing excellent care to the children, and the children were making progress. This rate was roughly the same for Kinship Care and Home Based Care, at a little under half of the placements in each case.

2. Summary of identified needs

Across all the programs the most common unmet needs were for:

- respite care, especially in the out-of-home care services. This was identified as an unmet need in a total of 10 placements.
- additional support so that children and young people could participate in social, recreational and cultural activities. This was an identified need for 29 young people.
- improving the interface between DHS and Disability Services, or Disability Services at the state level and the out-of-home care service.
- educational assistance. The qualitative comments provide further support of the data, presented in Section 1.8, that a number of children and young people needed additional educational assistance if they were to achieve at school.

3. Placement breakdowns and threats to placements

Twenty-five of 52 children who had a disability and experienced placement breakdowns did so with their disability contributing to the placement breakdown. Additionally, workers made comments about the insecurity of the placement because of the disability in seven cases in Disability Services, one in Home Based Care, and one in Kinship Care.

2.2 Findings from the care plan templates

Workers filled out a care plan template for the child in their caseload identified as having the most serious disability. The following findings emerged from these data. The resulting group contained 38 children, across all programs. The group's size was roughly proportionate to the number of children with a disability identified for each program, as shown in the Table 16, with Disability Services not being required to meet their target because of the large impost this would have been on worker time.

Table 16: Number of care plan templates filled in per program area

Program	All disabled children		Care Plan Sub-group	
	Number	Percent	Percent	Number
Disability Services	70	**35%**	**31%**	12
Home Based Care	55	**28%**	**28%**	11
Kinship Care	37	**18%**	**21%**	8
Family Services	22	**11%**	**13%**	5
CVCAL	8	**4%**	**5%**	2
RTO	8	**4%**	**2%**	1
Totals	200	**100%**	**100%**	39

Analysis of the data showed that a variety of specific goals were set, individually tailored to the situation of each child, family and care context, as would be expected. There was a strong emphasis on case management functions in the listed interventions. The case studies appeared to be a better vehicle for describing the full range of interventions, skills and knowledge employed by the workers to assist the children, their families and carers.

The most interesting data related to challenges and barriers to goal achievement, especially identification of service system gaps and difficulties, and worker rating of achievement of goals, despite the barriers.

2.2.1 Identified challenges to achievement of goals

Challenges and barriers were identified as coming from the child's disability, their family, home and care context, problems with OzChild's services, service system gaps and service system difficulties.

A total of 104 barriers were identified for the 38 children. Twenty-nine barriers originated in the nature of the child's disability or accompanying health or other child-specific circumstances, in interaction with their environment, including the service system. The family presented 17 barriers, and three carers were facing significant overload. Service gaps presented 25 barriers, service difficulties another 25, and five barriers originated in OzChild services.

To take the last mentioned first, the comparatively small number of barriers to goal achievement identified in OzChild's services included: workers' lack of knowledge about disability and disability services (two staff); tensions between the carer and Ozchild (one case); a carer's full-time employment presenting problems for providing adequate support (one case); and staff turnover (a problem for one family in one program).

Service gaps and difficulties were identified in 25 instances. The most frequently mentioned were:

- inadequate funding to cover the child's needs, which emerged as a problem in Family Services and Kinship Care. This problem could be inferred from at least half of the Kinship Care templates.
- lack of services for families with complex needs. This was especially a problem in Family ervices, being identified in 3 of the 5 Family Services templates, but also emerging through the case studies in some of the birth family situations.
- lack of respite services, identified principally in Disability Services (four of the 12 templates) but supporting the findings from the spreadsheet data identifying this as a problem in Home Based Care.

Other gaps were mentioned in only one or two cases and included: lack of outreach or in-service social work

and psychologist services for children and young people; inadequate early intervention services for families; shortage of specialist/trained carers for very high care need children; poor public transport; geographical isolation/rural lack of services; funding for permanent carers of disabled children; complexity of funding between different systems and eligibility issues; and financial and housing support for very poor carers. Although each item in this list of difficulties was only mentioned in one or two cases, every template identified some gaps. They amounted to barriers to achieving optimal capabilities for children with a disability of some sort. It is difficult, however, to set out clear recommendations about priority gaps that must be filled. The alternative approach is to convert the rhetoric of 'wrap around services to meet every child's needs' into reality. This would require a much more flexible system than the one we currently have. And in areas where there is a lack of specific services in the public system, brokerage is needed so that carers can access services for their children.

Twenty-five instances of service system difficulties were identified, with eleven of these relating to case plan failures of some sort. Five of these were in Kinship Care and six were in Disability Services. Case plan difficulties included: communication problems in the care team, including problems in coordinating multiple players; case planning failures such as cancelled meetings; perceived failure to listen to carers and workers; DHS failing to gain referral and access to services or to provide a particular service; and conflict over access between OzChild and DHS. Other difficulties included staff turnover in various agencies, including DHS; conflict between specialist services and carers over a diagnosis; insufficient time for case workers to meet the needs of the child; long waiting lists for dental services in one case and orthopaedic services in another; the child and family falling between cracks in the service system (for example, having needs that are too complex for local government universal services, but deemed ineligible for specialist disability services); insensitive,

2.2.2 What was done to overcome the barriers and challenges?

The educational services used their services to try to address the challenges and barriers. There was under-utilisation of other services to assist these young people.

The other programs used a combination of persistent and consistent case work and case management to overcome the barriers and challenges.

2.2.3 Outcomes achieved

Data from the 38 children showed that some excellent work was being done by carers, birth families, and OzChild staff and programs to meet the needs of children with disability. Across the six program areas staff rated the effectiveness of their intervention as highly or moderately effective in 34 of the 38 cases. Barriers and challenges were consistently addressed through persistent case work and case management processes. And about half of Home Based Care, Disability Services out-of-home care and Kinship Care placements were meeting the needs of children with very high needs at a level that reduced challenging behaviours and other effects of disability. Children were achieving at school, and participating well in the family and in cultural and recreational activities. These included several children with experiences of trauma with resultant complex and challenging behaviours.

2.3 Findings from the case studies

2.3.1 Description of the five children

Five case studies were undertaken, one each in Home Based Care, Kinship Care, Disability Services, Family Services and CVCAL. A benefit and problem with presenting findings from case studies is that the data is 'thick' and rich (Geertz, 1973). The benefit is that the data enables the sharing of knowledge and skill between workers, promotes conceptualisation, exploration of complexity, identification of processes of causation, and processes involved in achievement of outcomes. Nonetheless, the same data means that individual children and families may be identified. Thus, here we provide only a brief disguised description of each child as a backdrop to generalised findings extracted from the comprehensive and detailed data of the five case studies. The case studies of two children are selected and presented in greater detail later in the report because they demonstrate clearly some of the generalisations, and support findings from the rest of the research data. These two cases are heavily disguised.

Child 1 was one of two siblings placed with the same carer. The child was severely disabled, the sibling was not. The child with the disability was fully immobile and non-verbal. The children's parents had migrated to Australia; English was their second language, and they married and had their children in their forties. Their marriage broke down in an extremely acrimonious fashion, and the children became caught in the conflict, with each parent maintaining that particular parts of parenting were the other's responsibility. The children were reported to Child Protection after they were effectively abandoned. A complicated legal situation ensued with uncertainty about the children's legal status as a result of continual litigiousness on the part of one parent. This was still unresolved at the point of the case study, although it seemed unlikely that the children would return to the care of either parent. There were complicated cultural questions and suspected mental health issues for the parents. There were also questions of jurisdiction and responsibility between mental health, Child Protection, the agency (the case was contracted for one child but not the other) and the carer.

Child 2 was severely disabled, being immobile, non-verbal, P.E.G. fed, and with severe intellectual disability. The child had been with the same carer for 4 years, after spending the first 4 years of her life in hospital, because of the severe threat to her life posed by her physical condition. Her carer was in her 60s and faced a serious health crisis, but remained very committed to the child.

Child 3 was a preschooler with severe autism, but with some areas of high functioning. This child was cared for by relatives who had a large family of their own, and had cared for the child since infancy. Latterly they had also taken the child's two siblings into their home. These two children both had experienced trauma from sustained family violence, and both suffered attachment disorder and developmental delay. There was conflict in the wider family about the three children and their future, and the carers faced substantial financial difficulties in their family business, exacerbated by the financial demands of caring for the three children.

Child 4 was a primary school aged child with intellectual disability. The child was eligible for services through DHS Disability Services. She attended a special development school. Her mother also had disabilities as a result of long-term child abuse in her own childhood. The child's father came from a family with a history of substance abuse and family violence. Both families had been involved in the child protection system for at least 3 generations, and were highly suspicious of welfare services generally, and Child Protection in particular.

Child 5 was an adolescent with suspected mental health issues as a result of some severe grief and loss experiences. He was living with his grandfather, was acting out at school and failing to learn, and there was suspected substance abuse.

A variety of findings emerged from the case studies.

2.3.2 Findings about case practice – requirements, achievements and efficacy

Findings:

- Highly specialist knowledge and skill were required of generalist workers where a child had a severe disability. This was the case in all four of the non-disability program case studies.

- All workers demonstrated high levels of skill and knowledge at various levels and were able to achieve significant outcomes for the child and their family or carer.

- There were additional time demands on a case worker if a child in their caseload had a disability. This included additional time to relate to a child with severe communication difficulties, additional time to seek out resources for the child and family, and additional time needed to case manage the variety of service systems that intersect to provide resources to the child and family or carer. This issue emerged in all five case studies.

- These time demands were exacerbated when the family had multiple members with a disability or a range of disabilities. This emerged as problematic in two of the case studies.

- The pressures on the case worker were intensified when the child was a client within a program area

that had limited flexibility of program model. For example, foster care placements are ranked as general, intensive or complex, with each ranking attached to increased funding and resources for the placement. No such standard distinction is made for kinship care placements. Instead, Kinship Care workers had to argue the case for extra resources on a case by case basis. Family Services have the ability to provide longer term services or increased intensity to more complex families, but must balance efforts to do so against meeting overall program targets. This limits program ability to fully respond to the needs of highly complex families.

- The complexity of the cases meant that staff needed high levels of flexibility and multiple skills at different levels: individual, interpersonal, family, organisation and system. This was evident in all five case studies, as the following examples demonstrate.
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Example 1: Home Based Care. The sheer severity of the child's multiple disabilities necessitated development of sensitive attunement to a non-verbal child. It also involved strong case practice to gain resources necessary to maintain the placement, while, in the meantime, desperately supporting a carer with increasing health concerns. It involved learning and teaching a new way of relating to the child to promote increased communication, learning of some vocabulary, and sociability.

Example 2: Disability Services. The case involved care of a severely intellectually and physically disabled child; maintaining support of a carer who would have moved to permanent care had permanent care been sufficiently funded; understanding cultural issues for the birth parents; handling one extremely distressed and litigious parent and one disengaged one; and managing Child Protection, the Community Services Organisation, and DHS-Disability Services interfaces amid unresolved legal issues concerning the child's custody.

Example 3: The Family Services case study presented particular challenges when severe disability was just one of the strands of complexity for this family with chronic, multiple, severe and intractable problems that appeared across generations, and which included substance abuse, family violence, severe child abuse for the parent generation in their own childhoods, acquired brain injury, abuse induced vision impairment in one parent, poverty, and fear of service providers. The worker also needed to understand the active contribution of an extended family on both sides of the family to the current family situation – with both positive and negative effects.

- Effecting change in specific and minute case, age-stage, and child-carer components were prerequisites for achieving higher order outcomes. Making progress in each of the components was an intricate and skilful job, sometimes being provided over years. Without this skilful intervention, higher order case, program and system outcomes could not be achieved. This was evident in all five case studies. For example, in the Home Based Care case study, the higher order desired outcomes included stability, permanence and optimal development of the child. The prerequisite components involved establishing attachment for a severely disabled child with hearing and sight difficulties as well as severe intellectual disability; specific programs of stimulation and communication; and coordinating intensive interactions between carer-child, worker-child, teachers-child and the whole school program to maximise opportunities for socialisation, communication and stimulation. This took place in the context of serious physical threats to the child and a medical program of life-threatening surgical intervention. It also involved persistent case management and advocacy efforts to ensure placement support in terms of regular (weekly) respite care to protect the health of the carer.

- Working with these children with disability required a different valuing of 'progress' and 'development' as both are anormative for many children with a disability. There is a need to value snail's pace progress, and to rejoice in small signs of movement. The generalist and disability specific staff were all able to do this, but it meant consciously shifting to a different frame to do so. This needs to be factored in at program and service system levels.

- The vast majority of the generalist staff involved in the case studies had a very strong commitment to learning more about disability and to ensuring that the disabled children with whom they were involved received the best service possible. Staff were prepared to invest significant personal as well as professional time into developing knowledge and skill. (This was especially evident in three of the five case studies.) There was a need for OzChild to invest financially in staff development, as identified here and in other components of the research project.

- Specific interventions were required to ensure children with a disability maximised their learning and participation in education. Specific interventions related to particular disabilities. Some carers needed assistance and knowledge so that they could support their child's learning. This was particularly so with the child in Home Based Care with the enactment of the intensive interaction program, with the autistic child in kinship care, and with the child with an intellectual disability in a very marginalised and excluded family in Family Services. Each worker had to institute interventions completely different from each other to maximise the learning and development of the particular child.

- Workers, be they in disability specific or generalist programs, needed strong advocacy skills at the case level to ensure the various systems responded to the needs of the particular child and family or carer. The need for such advocacy was evident in all five cases. So too was the draining and time-consuming nature of such advocacy efforts.

2.3.3 Findings about service system functioning

- Services for birth parents of children in care were severely limited, and very difficult to access for families who were highly suspicious of or hostile towards services as a result of their children being removed from their care. Such parents can miss out on services with consequent difficulties for other services trying to maintain the relationship between the child in care and its parents. Problems of accessing appropriate services are exacerbated if there is no plan to reunify the child with its birth parents. This was a very significant issue in the Disability Services case study. While many out-of-home care providers provide a limited service to birth families, services are not funded to provide the specialist and time-consuming service required by some highly complex families to maximise relationships between the child and their birth parents.

- There was evidence that access to services by birth fathers in both out-of-home care and family services is still problematic (the case in the Family Services and Disability Services case studies). In one case neither DHS nor OzChild was able to engage the father. In the second case, OzChild was making progress in this area, but the father remained disengaged from other services.

- A guaranteed and integrated family focussed approach across multiple services was lacking, particularly within adult services. This was evident in three of the case studies: Disability Services, Family Services and Kinship Care. Mental health services, disability assessment services and substance abuse services all struggled to provide a family-friendly or inclusive service. Funding arrangements sometimes mean it is difficult for child focussed services to maintain a family focus. For example, there is limited capacity for foster and kinship care services to work with birth families.

- There were serious problems at the point of intersection of systems, with carers, families and workers navigating a myriad of services that nonetheless did not fully meet the needs of the child or family or carer, and did not relate seamlessly to either other workers in the system or to the child, family, or carer. This was the case, at least to some extent, in all five case studies, sometimes to the extent that it became impossible to achieve set goals. The most serious difficulties were that good assessment did not translate into access to recommended services, and that children fell between the cracks of service systems, whether between Ozchild and DHS, between disability and child protection services within DHS, between government departments, between services targeting different age groups (early childhood education services and primary and secondary schools), or a combination of these.

- There were multiple barriers to effectively meeting the needs of severely disabled children and young people for social inclusion and participation. This was particularly evident for four of the case study children. The two children in Home Based Care and Disability Services faced barriers because of the sheer severity of their disabilities. The Kinship Care child faced barriers because of the nature of the disability (severe autism) and lack of supported recreational opportunities in a rural setting. The Family Services child faced barriers in part because of the cultural context of the family – intergenerationally excluded; disadvantaged and marginalised; lacking skill in social interaction; distrustful of schools, organisations, and people generally – and the difficulty of the worker in bringing about change in these areas while tackling difficulties of immediate safety and development for the child and her siblings.

2.3.4 Findings about funding and resource provision

- Funding and resource allocation inequities skewed intervention with sometimes negative effects on relationships within the care team. For example, reduced levels of funding for placement support and support packages to address the child's needs meant some children stayed in foster care rather than entering permanent care placements. Not only is permanency denied the child in these cases, but carers who otherwise would be raising a child without input (whether seen as positive or as interference) are locked into a support relationship whether they see it as necessary or not.

- There are inequities in funding for children with similar difficulties in different programs, with some children and placements not receiving the level of support needed to meet the needs of the child or carer. The differences between actual funding levels for kinship care, compared to foster care, or to a permanent care placement, have already been raised.

2.3.5 Outcomes

Two areas of interest emerge. The first relates to outcomes achievable with severely disabled children by generalist program staff – in OzChild's case, Family Services, Home Based Care and Kinship Care staff. The second relates to a particular problem that emerged in all five case studies: the barriers to achieving specified outcomes for children and carers or families at the point of intersection of systems. How did this actually affect the extent to which practitioners could achieve the goals set for particular cases?

Two case studies, one in foster care, and the other in family services, provide a particular context for this discussion.

The first case is illustrative of a group of 19 of the 200 children, who had severe and complex physical disability and severe intellectual disability. The majority of these children were cared for within OzChild's Disability Program, but five of them were in the Home Based Care program. Suzie was one such child.[4] She was 12 years old. She was born with a severe physical disorder which left her needing to be P.E.G. fed, with no mobility, severely intellectually disabled, non-verbal, and with hearing and sight problems. Suzie had been with the same carer, a woman now in her 60s, since she was two years old. Her first two years were spent in hospital because of the severity of her physical disorder and the ongoing threats it posed to her life.

The second case of an early primary age child, Skye, illustrates the difficulties presented by families with multiple, chronic, entrenched and seemingly intractable problems appearing across generations. This case presents the struggles of a family in Family Services, and their worker. The family had multiple family members with multiple disabilities – Skye was intellectually disabled, and with suspected autism. Her mother was legally blind as a result of severe physical abuse during her own childhood, and with suspected Acquired Brain Injury. Both her parents, and grandparents on both sides of the family, had had a great deal of contact with Child Protection Services, with her mother's family being extremely reluctant to receive services from any Family Services program. Her father's family was from a close-knit immigrant cultural group, but with a long history of substance abuse and family violence across at least two adult generations of the family.

The question of outcomes – the case of Suzie:

Practitioners collect valuable data about the achievement of outcomes, since they spend time with children and families and can observe changes that occur. The case study process accessed this data. Case study also enables a long view of time. In this case study, the course of a placement reviewed was of 10 years duration.

One carer maintained her care of Suzie for 10 years, with casework support ensuring access to all services for which she and Suzie were eligible. Suzie thrived, within the limitations of her disability, outliving all predictions of life expectancy. She grew strongly attached to her carer, and was secure in this family setting. But the worker saw the stress of the placement on the carer. Renewed efforts were made to access more support for her, to no avail. The carer had a physical health crisis, required hospitalisation and a period of recuperation. Because of the severity of her disability, Suzie was placed in a residential care setting during this time. The facility provided excellent care, but Suzie became significantly depressed – her attachment was to her carer. When the carer had recovered, she concluded that she could not resume the care of Suzie, unless additional supports were in place. Only in the face of actual placement breakdown, with a carer unable to resume the care of Suzie, were resources for every-weekend respite able to be approved. The

[4] No real names are used. Case details have been disguised in both cases.

placement continues.

One finding from this data is that some system level outcomes were achieved: prevention of placement breakdown; prevention of the cost of residential care; and eventual preventive intervention to protect the health of a carer.

There are also findings about outcomes achieved for Suzie. Secure attachment was achieved for Suzie, despite the barriers to attachment presented by her disability. Mental illness, in the form of depression, was averted – her depression vanished on her return to her carer. Susie's health was maximised – she has surpassed her life expectancy. Further, Suzie's worker, carer, the carer's family and school alike were all concerned to promote optimum development for Suzie. This is an outcome that will continue to be a focus for them, throughout the entire period of Suzie's childhood, and beyond. A new program of intensive interaction was instituted, through which Suzie developed two words, became comfortable in the presence of strangers, and began to seek interaction through vocalisation, and to 'converse' with those prepared to converse with her – for up to 40 minutes. These developments of words and increased sociability were measurable over a 12 month period.

The skills of the carer, her network (specifically her close extended family), and of the worker, can be identified. The carer and her family were totally committed to Suzie, seeing her as an equal member of their network. The carer and her brother have been very strong in advocating for Suzie, and also for getting supports for the carer, so that she can continue to care for Suzie, without killing herself in the process. The worker has taken a strong advocacy lead in this work too. In addition, she has sought knowledge of how to communicate with such a severely disabled child, undertook training, instituted the program, encouraged the carer to do likewise, found the school was following the same program, supported their efforts, and has seen the resultant change and development in Suzie. Her commitment to learning, to this child with her particular disabilities, and to making a positive difference for her is evident.

2.3.6 Problems at points of interpenetration of systems, and their effects

Example 1: Suzie:

Suzie presents one set of problems at the intersection of services: the inability to access sufficient support for a placement until a devoted and committed carer is put in the position of having to refuse taking a child back into her care after a period of illness. At this point, resources for sufficient respite care could be found.

Example 2: Skye:

Skye and her family present another set of common case work challenges. Skye's family's long history with Child Protection and other welfare services meant that accessing any service for them was deeply affected by hostile past relationships. Everyone was edgy about accessing services. Skye's mother needed assessment for acquired brain injury, but such assessment was expensive and there were waiting lists. She could be given priority, especially given the threatened removal of children from her care, but her poor relationships with Child Protection were a barrier to accessing the support Child Protection would no doubt provide. She needed specific vision services, but these services found her hard to understand, and did not offer in-home services in her area, which she sorely needed. The special school that Skye attended was highly critical of her family, and made efforts (strongly and successfully resisted by the worker and the family, because Skye was doing well in this setting) to move Skye to a different school. Additionally, the worker was in the process of ensuring that Skye was on the Disability Register, after which Skye's mother would be eligible for a Carer's allowance, which would ease some of the financial stress being experienced in the family. Skye needed assessment in relation to suspected autism, but the worker suspected, from her experience with other cases, that accessing services following the assessment would be a challenge.

Skye's parents were separated. Skye's father was in need of both family violence and substance abuse services. Without them, Skye would not be able to develop a safe relationship with him. Services involved with her father would need to have an understanding of the family context and family goals.

The situation was not without some positive elements. Skye's mother engaged with the Family Services worker – the first engagement with services in many years. It took a great deal of worker time, effort,

consistency, reliability and honesty to get to this point. The family were involved with the service for much longer than is usually allowed in Family Services, which entailed the program having to balance pressures about achievement of throughputs (targets) with outcomes (Is Skye safer? Is her mother a better parent?). Skye's mother was, with a great deal of support, accessing some services. Skye's maternal grandmother was allocated a worker with the objective of building a more positive relationship with her daughter (Skye's mother). Skye's father's family continued to be supportive of Skye and had her stay at their home every second weekend. They were involved in more positive networks since becoming involved in a Christian Church, and were no longer involved in substance abuse and violence. They were protective of Skye in relation to her father, encouraging contact when he was not substance affected. These positive relationships have been fostered by the worker, in collaboration with a family conferencing program within DHS.

Example 3: Disability Services:

The Disability Services case study also presented a very complex situation of a complex network of services that was not meeting the needs of the children or their birth parents. In the midst of lack of clarity about the future care of the children, one of whom was severely disabled, services failed to engage either parent, one of whom was highly litigious. The children remained on an Interim Protection Order for a period of years. Mental health services failed to engage one parent who stood in clear need of assessment. Culturally knowledgeable and sensitive services were not available for either parent, yet both had arrived relatively recently in Australia, and came from a non-English speaking background. Case management of the two children rested with two agencies. Disability Services and Child Protection both needed to be involved with the family. Managing this situation for the foster carer was extremely difficult. She had had the two children for a period of years, but their future with her was unclear because of the unclear legal situation.

These elements conspire to make case practice extremely challenging and frustrating. They also present daily threats to achieving stability, family connection and identity, and the children's safety. They also make it very difficult to meet the needs of the birth parents in any way.

2.3.7 Funding Inequities

Example 1: Disability Services:

In this case, the carer would have preferred to become the permanent carer of the two children, had the legal situation been resolved. However, if she did so, she would lose essential funding, because of the disparity between a Family Options package and permanent care funding. The disparity meant that, even were the legal status of the children resolved, and a Permanent Care Order issued, this committed carer would not have been able to move to permanent care. She needed the additional funding available through Family Options to care for the child with the severe disability.

Example 2: Kinship Care:

The child in Kinship Care presented serious challenges to his carers. They were experiencing financial hardship, while spending additional resources on the child's needs that arose specifically from severe autism. The carers had cared for this child since early infancy and had recently taken on the care of two additional siblings, both with experiences of trauma. Yet the kinship care placement was funded only at the 'General' level of foster care funding, despite attempts by OzChild to access increased funding. All three children, if placed in foster care, would have received a higher level of funding. The placement of all three children is under threat in the longer term, if such inequity of funding continues.

2.3.8 Recommendations from the case studies

The case study material provides support for a number of the recommendations that emerge from the other parts of the Research Project. From Suzie and Skye we can see that there is need for training and professional development for staff in non-disability services that builds on existing knowledge and commitment to children with disability. The additional time workers need to address the added complexity of cases where there is disability must be factored into targets and caseloads, and therefore into program funding. A different program model is needed for families like Skye's – one built on the premise that more than one worker will be needed with these families, and that processes of exclusion will have to be addressed as part of the intervention. This will necessarily involve tackling the educational disadvantage and chronic

long-term unemployment of parents, and their lack of skill in community participation – be that through involvement in their children's schools, education, training, employment, voluntary activity, or cultural and recreational activities.

Further, both cases illustrate the difficulties that arise between the different services that are designed to help such children. This is not a matter of greater coordination between or integration of services and service systems. It is a question of building systems where the child and family are not seen as separate entities, but rather as a whole unit. It also requires a system where people are not divided into unrelated parts at each service door – a blind person here, a person with acquired brain injury there, a person who needs to learn different parenting strategies somewhere else, or a person with a substance addiction in yet another setting.

The Disability Services case study shows the need for additional services for birth parents with high levels of complexity, if we are to maximise relationships between children in care and their birth parents.

The Disability Services and the Kinship Care case studies show the need to address inequities in funding between foster care and kinship care, and between both and permanent care.

Section 3: Discussion, Conclusions and Recommendations from all the data

3.1 Discussion and conclusions

While a number of the findings from this research will not surprise those working in the field, they present some challenges for practice, program design and policy. Discussion and recommendations apply to the context of Victoria, Australia. We limit ourselves to seven areas of discussion. Further, this report should be read alongside recent reform initiatives from the Cummins Report, DHS structural reform, Services Connect trials, the five year out-of-home care plan and the Shergold Report, the outcomes of which are still to be evaluated. Some recommendations reported here are congruent with these various initiatives but others identify the need for additional responses or resources. All are designed to improve outcomes for children with disabilities in whatever service they appear.

3.1.1 The high proportion of children with disabilities in our services and the extensive variety of disabilities experienced by children in all program areas

On the one hand, policy makers and service system designers acknowledge that disability requires specialist knowledge and expertise, with specific services established for those with disabilities. Yet the data from this study show that generalist practitioners in a variety of program areas – foster care, kinship care, family services and educational services – are dealing with children with a huge variety of disabilities, across the spectrum of seriousness. Generalist staff do not necessarily have disability-specific knowledge. Program and practice models are needed that allow them to access specialist knowledge and information swiftly, both about the particular disability and its effects, and about the services that are available for each child. Staff require time to acquire this knowledge. One size will not fit all, and systems must to be in place to address the situation workers actually face when a child with a particular disability comes into their caseload. The case study component of the research found that staff in different program areas had program-specific knowledge, which, when shared with those in other program areas, resulted in a much deeper understanding of the child and their situation. There were consequent expanded possibilities for intervention. Yet opportunities for sharing case and service system knowledge are limited, with one of the major constraints being lack of time as a result of high caseloads. If children with disabilities are to receive maximal care, program models need to allow staff the time for these tasks and activities.

Staff also need to be able to spend additional time with children and their families or carers to both assess and address the additional needs of those with disabilities and those caring for them.

The findings suggest that current program models and service system responses do not adequately cater for the extensive variety of disability and levels of seriousness identified in this study. These require particularised, flexible and responsive practice models, programs and service systems tailored to the needs of each child and their family/carer, and to the challenges each particular disability presents to both the child and their carers.

The sheer number of children with disability in this sample, combined with the spread of children with a disability across all staff in all programs, makes it difficult to avoid the conclusion that additional funding is needed: for development of program and practice models of greater flexibility; and for time release and backfill for knowledge and skill transfer for all staff.

3.1.2 Conclusions about the ADHD co-morbidity data

The complexity of ADHD presentations, with such a high level of co-morbidity, may suggest that a better understanding of ADHD and its relationship to trauma, attachment and the causes of other learning and behavioural difficulties are needed. The findings suggest the need for continuing multidisciplinary theoretical, conceptual and research efforts in relation to ADHD. In the meantime, practitioners need support to view ADHD through multiple lenses, to acknowledge the range of interventions that might be helpful, and

to have the confidence that professionally-based trial and error learning is a professional responsibility in such a situation.

3.1.3 Conceptualisation and origins of, and pathways into, disability

The data about the contribution of the child's environment to disability and the specific data about excluded families call for greater thought within the sector about:

- a definition of disability in terms of functional impairment, rather than diagnosis;
- pathways into, or origins of, disability for a substantial number of children; and
- particular macro-level prevention strategies, and multilevel early interventions that would prevent a substantial proportion of disabilities in children in child and family welfare services.

Incorporation of functional impairment in definitions of disability:

Functional impairment should be the central descriptor of all disabilities, delays, and disorders, because diagnostic terms are only significant for a child, parent, carer or community to the extent that they affect the child's functioning. Deciding to intervene, help and support the child should be dependent on an understanding of that particular functional impairment in each case. If the child's behaviour is the same, whether the diagnosis is autism (currently eligible for Disability Services) or reactive attachment disorder (currently ineligible), the child and their parent or carer need help and support (Pitman, Martin, & Mitchell, 2013).

Pathways into disability, prevention and early intervention:

Cause, prevention and intervention are themes that intertwine in this discussion. The findings of this study highlight the multiple causes of disability in this particular cohort of children. Some disabilities are genetic. Some are caused by particular physical illnesses and biological processes for which we currently have no cure or ability to prevent. And regardless of cause, children with similar symptoms needed services that would reduce their disability, and/or the effects of the disability on them and their carers. Cause, however, is relevant at two levels. First, it is important in deciding whether children presenting the same symptoms will respond to the same intervention, regardless of cause. Second, it is important in defining effective prevention and early intervention strategies – at both macro and family and individual child levels.

The findings showed that the different origins and pathways in some instances called for different responses, and in others, identical intervention, once the disability was established. The data on educational achievement and connection to the community for this cohort of children were clear: in many cases, and regardless of cause, such interventions needed to address barriers to educational achievement and social connection and participation.

Focussing on cause allows identification of some disabilities that result from processes that are, at least theoretically, preventable. Accordingly, questions of prevention must be addressed. If cerebral palsy is caused, in some cases, by birth trauma, effort must be devoted to minimising the number of births where that kind of trauma occurs. If road trauma results in acquired brain injury, a society will try to reduce the number of road accidents, and introduce all sorts of safety measures, such as airbags in cars, to reduce trauma when accidents occur. If developmental delay, learning problems and some childhood mental illnesses are caused by child abuse and neglect (which in turn may have their causes in a number of interrelated dynamics at the intra- and interpersonal, family, and societal levels), then strong efforts must be devoted to addressing these causes. Many efforts in Australia and elsewhere are, of course, devoted to just such prevention. The findings from this study merely underscore the fact that more needs to be done.

A subset of families called excluded families, where disabilities are environmentally based, have been highlighted. Mitchell and Campbell (2011) argue that excluded families represent a significant subgroup of families in the child and family welfare system that presents the field with major challenges in achieving positive outcomes for either the parents or children. They and many others identify the contribution of forces well outside the control of any family in creating and maintaining exclusion (Sen, 2001; Spencer & Baldwin, 2005; Taket, Crisp, Nevill, Graham, & Barter-Godfrey, 2009; Tierney, 1976). These forces include

poverty, educational disadvantage, racism, marginalisation, chronic structural unemployment and lack of affordable housing. In this study, all but one child from excluded families in Family Services had disabilities that were environmentally based. We assume that many children in Home Based Care with environmentally based disabilities came into care from excluded families.

If the number of children in care and the number of children with these particular disabilities are to be reduced, there is an obvious need to address the causative factors of exclusion at a societal level. There is a need to effectively intervene in the cycles that create excluded families and which place their children in environments that, in turn and over time, create disability in children. In part this will mean addressing societal factors that contribute to poverty, such as structural unemployment, homelessness and racism. Concurrently, it will require more effective intensive intervention with families who are identified as excluded, for greater lengths of time, to address the effects of poverty, marginalisation, intergenerational abuse and trauma on individual and family development. That is, there are at least two relevant levels of prevention: the level that addresses the societal factors which contribute to and help maintain exclusion; and the level that helps families and individuals embedded in exclusion to move out of it. This will, of necessity, involve ameliorating the destructive effects of poverty, marginalisation, violence, substance abuse and mental illness on individuals and families, and on their developmental pathways.

3.1.4 Educational achievement

This study confirms findings of other research that too many children in child and family welfare services continue to fail at school, and will continue to do so unless we find better ways of helping them. The findings suggest that there is a need for increased knowledge and skill in teachers and caseworkers about particular disabilities and their effects on learning and participation. Given the number of children with an aide or already in a special school setting who continue to not achieve in their placed grade level, exploration of additional interventions and programs, and subsequent evaluation of these to build a bank of effective interventions when children are not achieving at school, are essential. While some innovation as well as knowledge and skill sharing and development are possible within existing funding arrangements, additional funding would foster development of alternative educational programs within existing and alternative educational settings. Additional support programs outside of the educational setting, either in the home or the community, were also indicated for some children.

3.1.5 Inability to participate in social, cultural and recreational activities

Barriers to participation emerged as a big issue for a large subgroup of the children. It was very clear that some children needed additional help or different activities if they were ever to participate in their community, whether in extra-curricular activities at school or in their community more broadly. Given the variety of disabilities and resultant variety of barriers to participation, there is a need for some diverse, targeted anda pilot programs to explore a range of effective interventions to connect children with a disability in child and family welfare services to their communities.

3.1.6 Funding inequalities

Two of the case studies and a number of children in the Kinship Care cohort demonstrated difficulties that arose for children and carers as a result of different funding arrangements for permanent care, kinship care and foster care. There were some carers and children with highly complex needs in the Kinship Care group for whom it was difficult to access much-needed resources. DHS policy is that all children placed away from their birth parents are to be funded according to need; however, kinship care is funded from a different budget than foster care within DHS, and policy decisions are enacted at the geographical divisional level. In this study, it appeared that lower and more inflexible funding for kinship care occurred at the operational level. There is a great need for kinship and permanent care placements to be funded according to need, at least at the level provided to foster care, in a completely transparent process, where guidelines and processes are articulated and publically available, and where there is state-wide equity of funding.

3.1.7 Problems at the intersection of services

The care plan data on the sample group of 38 children and the five case studies demonstrated that significant difficulties for children, carers, families and case workers occur at the points where different services intersect to provide what is meant to be an integrated and holistic service. The experience of carers, families and workers is that the service system operates neither seamlessly nor holistically, but rather that children and adults are divided into parts and each service intervenes only in a part of the person's life. It is very difficult to get everyone working in the same direction, and carers, families and workers often have to spend a great deal of time with all the different services, and in making the contribution of each make sense.

3.2 Conclusions and recommendations

We acknowledge the effective intervention within existing funding arrangements and program and practice models for children with a disability. However, the findings from this research suggest that more is needed to promote improved outcomes for children with a disability in child and family welfare services within Victoria.

Clarify definition of disability:

- Include functional impairment, regardless of aetiology, in the definition of disability and in eligibility criteria for disability services.

Prevent:

- Prevent disability through macro-level strategies to reduce environmental factors that contribute to the development of disability: poverty, racism, marginalisation, chronic unemployment, homelessness and lack of affordable housing.
- Prevent environmentally based disability at the family level through a more targeted approach to families with multiple and complex needs. The approach must be tailored to their needs and history, providing more flexibly intensive intervention for longer periods of time, embedded in a family centred, ecological, cultural, developmental and competency based approach.
- Prevent placement breakdowns for children with a disability through appropriate levels of support targeted to placements at risk of breakdown.
- Evaluate pilot projects developed collaboratively with the non-government sector to explore a range of innovative program models to find new solutions to the unsolved problems of excluded families – those with chronic, complex and multiple needs.

Construct accessible and holistic adult and child services:

- Build service systems around children and families which respond to the whole child or adult, and which take a family focus.
- Improve access of fathers to services.

Prioritise resource allocation to child and family welfare services:

- Factor into program targets the additional time demands on workers with children with a disability.
- Provide additional resources for professional development in disability for staff in child and family services and alternative education settings.
- Review, enhance and develop approaches to assist children in out-of-home care and family services to achieve at school through partnership between the government and non-government sectors.
- Explore the full range of existing models and innovative proposals in mainstream, alternative and special schools in partnership between government and non-government sectors. Whether using existing or additional funding, develop a bank of effective interventions when children are not achieving at school. A range of models are available, including, but not limited to, additional aides in the classroom, educational workers for children in out-of-home care, and in-home tutoring and support.
- Apply current effective approaches and new initiatives arising from innovation to children with a disability.
- Promote innovation to develop diverse, targeted pilot programs to explore a range of effective interventions to connect children with a disability in child and family welfare services to their

communities.
- Ensure availability of respite services for carers of children with very high care needs.
- Ensure children with disabilities in kinship care and permanent care can access the same supplementary funding and resources as children with a disability in foster care; for example, placement establishment, flexi-pack and brokerage funding in all regions, state-wide, with clearly articulated guidelines available equally to all foster and kinship care agencies.
- Provide carer support to permanent carers and increase existing levels of carer support to kinship carers when either are in straightened financial circumstances and face additional financial demands as a result of a child's disability.
- Develop services for birth families with high levels of complexity who have had their children removed from their care and who have conflicted relationships with Child Protection and out-of-home care providers, to maximise constructive relationships between the children and their birth parents, regardless of placement type. Development of such services will require additional funding.

These changes, sufficiently developed and evaluated, would provide the foundation for achieving better outcomes for children with a disability in child and family welfare services.

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