



Supporting Families: Factors contributing to children and young people with disability living in voluntary out-of-home care

This report summarises key findings from a 12-month study commissioned by the Department for Communities and Social Inclusion (DCSI) and conducted by Novita Children's Services between October 2012 and July 2013.

The study supports one of the South Australian Government's key strategic priorities, Every Chance for Every Child, and is consistent with the National Research Agenda for Protecting Australia's Children, which identifies children with disability as a specific population of focus.

The study

The study explored the circumstances surrounding the placement of children and young people with disability under the age of 18 years in voluntary out-of-home care (VOOHC) in South Australia. In this context VOOHC was defined as a placement voluntarily initiated by a parent of a child or young person up to 18 years of age, without a court order (i.e. parents retain legal guardianship). The specific aims were to:

1. Explore the factors that contribute to families seeking VOOHC placement for their child with disability, including key triggers and 'tipping point' events.
2. Explore the experiences and consequences for children with disability placed in VOOHC, including the role of family contact.
3. Identify families' views on service and other supports that they have received prior to, during and after placement of their child with disability in VOOHC, including supports (if any) that would have assisted them to be able to continue to care for their child at home.

The study used a mixed methods approach including:

- a review of existing data for 31 children and young people on the Disability Services (DCSI) Out-of-Home Care Register¹;

¹ This confidential register is managed by Disability Services (DCSI) and includes details of all children who are placed in alternative care for more than 2 nights a week on a regular basis, and who are in care for more than 3 months.

- semi-structured interviews with 14 parents/ carers from ten families, four young people residing in out-of-home care, six accommodation service managers from non-government organisations who provide out-of-home care accommodation, and two Disability Services (DCSI) staff;
- three focus groups with Disability Services (DCSI) staff.

Limitations

This report does not include details of service improvements underway within Disability Services prior to the research commencing, including the appointment of a Lead Practitioner, Children in Out-of-Home Care, and the development of policy and practice guidelines for Disability Services staff.

The study is based on a small number of participants, therefore any attempt to generalise the findings to other contexts or settings is problematic. In addition, the qualitative nature of the study means that the views expressed by participants are not necessarily representative of all children, young people, families and staff. These limitations should be borne in mind when reading this summary.

Key findings

The factors that contribute to families seeking out-of-home placement for their child with disability, including key triggers and ‘tipping point’ events

The study identified factors, associated with child behaviour and/or characteristics, the family situation and the support context, that were seen as contributing to families seeking out-of-home placement for their child with disability.

Child behaviour/characteristics

Data review showed that children placed in VOOHC at the time of the study were more likely to be male, to have been placed in care between the ages of 12 and 17 years, and to have a diagnosis of autism (with or without intellectual disability). Most also had one of more physical or mental health conditions.

Challenging behaviours were the most prevalent concern cited by parents/carers of children with disability. Such behaviours ranged from violent or threatening conduct (with parents/carers reporting being “bashed”, “beaten up”, “[flung] across rooms” or threatened with knives) to young people having “meltdowns”, screaming, experiencing sleep disturbance, withdrawal, involvement with the youth justice system, and using drugs. Self-harm was another concern:

“[He/she] would scream for hours and bite [him/herself], leaving bruises all over [his/her] arms and legs” (Parent/carer interview 7).

The data review confirmed challenging behaviour as a major issue in seeking placement, with 81 per cent (n = 25) of families reporting “Unable to cope with/manage challenging behaviour” as the primary reason. Violence towards siblings was also raised in the interviews and confirmed by data review, which showed that in 36 per cent (n = 11) of families the placement was due to “physical violence towards siblings”.

The majority of parents/carers cited an increase in challenging behaviours as their child matured, particularly around the onset of puberty. Many noted that their child became more “physically demanding” and that previously successful behaviour management strategies were no longer appropriate or effective.

This trend towards more challenging behaviours as the child matures was also reflected in the data review. The younger the child at the time of placement, the more likely “self-injurious behaviours”, “self-stimulatory behaviours” and/or “property damage” was recorded on their file. The older the child at placement, the more likely “verbal aggression/threats” and/or “violent injury to others” was recorded.

This is consistent with previous research that suggests that the older and larger the child and the more challenging the child’s behaviour, the more likely it is that a family will consider out-of-home care (Llewellyn et al. 1999; Llewellyn et al. 2005). Nankervis et al (2011) found that being at or approaching the age of young adulthood was a factor that could contribute to out-of-home placement.

The child’s multiple diagnoses and/or additional physical or mental health conditions were a factor in decision making by some families. The added strain of day-to-day care responsibilities and the time required to attend health appointments were also contributing factors.

The family situation

Previous research points to carers’ psychological health (e.g. stress, exhaustion and depression) as factors that may contribute to the placement decisions (Nankervis et al. 2011). **Parents/carers** in this study also referred to their **health** as a factor in out-of-home placement decisions. One or both parents/carers in eight of the ten families interviewed reported a serious mental or physical health condition, such as depression, heart problems and chronic pain. Respondents often reported feeling “burnt out” and “exhausted”. Respondents described specific incidences where a child had been placed in out-of-home care entirely due to carer health issues. Indeed, the data revealed that for 39 percent (n = 12) of families, the reason for placement was due to “Parent ill health/mental capacity/age”.

In some cases, **parental capacity or resources** to take on advice or adopt strategies to manage their child’s increasingly challenging behaviour was considered to be a factor by staff. A number of parents/carers and staff mentioned that the presence of other family members with disability or serious health conditions added to the caring load and the problem.

Parents/carers also spoke of being unable to meet **siblings’ needs** as a result of the demands placed upon them by their child with disability. Parents/carers were concerned that siblings “had no privacy”, were “withdrawn”, “struggled a lot” and were “missing out” on regular activities, such as having friends around. Caregivers who experience increased concerns for the health and wellbeing of their typically developing children are more likely to seek out-of-home care (Llewellyn et al. 1999; Llewellyn et al. 2005).

Marital breakdown was previously identified as a potential contributing factor in the placement of young adults with disability in out-of-home care (Nankervis et al. 2011). In the present study parents/carers spoke of the significant strain of caring for a child with disability on their **relationships** with their partner and/or other family members, with some relationships breaking down completely. Staff provided examples of pressure within a relationship, resulting in a child being placed in care, particularly if one parent had found a new partner:

“The break-up of families is a significant reason why children end up in long-term out-of-home care. You might have a reason where the family has split up and neither parent wants to continue to have a role in their child’s life” (Accommodation service manager 6).

Several parents/carers noted that they had faced **financial pressures** when their child was living at home. Some had had to leave employment or reduce their work hours to enable them to care for their child, while others tried to maintain their job in the face of financial strain. Parents/carers spoke of significant costs related to medication, child-care, therapy and other support needs. Such economic and financial issues, impacting negatively on family well-being, have been previously documented by Parish & Cloud (2006).

According to the data review, over half of the families (52%, n = 16) had one or more environmental stressor(s) recorded, including family conflict, housing transitions/difficulties, parental separation, substance abuse and social isolation.

The support context

Data review indicated that a large proportion of families whose children were in out-of-home care were receiving services prior to placement. For example, 52 percent of families (n = 16) were involved with the Intensive Family Intervention Program (IFIP) and the majority of children (87%, n = 27) received assistance from Disability Services.

All but one family had accessed other formal services such as hospitals, Autism SA, private psychologists and/or counsellors.

Other service contacts included Families SA, with at least 36 percent of the children having notifications recorded (n = 11), and the youth justice system, with twenty-three percent of children having some involvement (n = 7), most often for assault (43% of those who had any involvement, n = 3).

Several parents/carers in this study felt strongly that they had received support. For others, though, the unrelenting challenges of the child's behaviour, coupled with an unmet need for support, was a primary factor in their decision to place their child in voluntary out-of-home care.

“Although we might have received more support and services than most families, it was still not enough to keep [child] at home” (Parent/carer interview 5).

Parents and carers highlighted that respite, or lack thereof, was a significant factor in the build-up of stress prior to placement of their children in care. Earlier research confirms that the risk of seeking out-of-home placement for a child with disability increases substantially when families lack support with child-care or respite care (Llewellyn et al. 1996; Llewellyn et al. 2005).

Study participants highlighted a lack of formal, planned respite arrangements as a significant factor in the build-up of stress prior to a placement. When respite was offered, it was deemed inflexible (e.g. only centre-based or overnight); and some families reported that funding was cut or they were informed, at the last minute, that their respite arrangements had been cancelled.

In addition, there was a perception that respite arrangements were inequitable, with those parents who lacked the capacity to advocate for their children missing out, a finding previously documented in a United Kingdom study (McGill, Papachristoforou & Cooper 2005).

All but one family interviewed spoke of the decision to place their child in out-of-home care as being “a last resort”. According to parents/carers, they had “tried everything” and “done everything” but “there was no relief” and they “didn’t know what else to do”. Consistent with previous research (Hare et al. 2004; Victorian Equal Opportunity and Human Rights Commission (VEOHRC), 2012), parents/carers conveyed a strong feeling that services only stepped in when it was too late, when the family was already in crisis:

“It felt as though there had to be a major crisis to get help – it took several years to get something that was helpful...we needed to go to extremes to get help and to wait until life was a complete mess and we were falling apart” (Parent/carer interview 10).

Staff acknowledged that many families could see “the writing on the wall” and sought additional help however, staff also reported that some families “came out of the blue”, a finding also reported by Nankervis et al. (2011). Such families had not raised the possibility of placement beforehand, and some had moved from interstate because they perceived that they would receive a better service in South Australia.

Many families experienced social isolation and were unable to access support. In some instances, extended family members fell away because they were unable to deal with the child's diagnosis or behaviour, or they lived interstate and were only able to provide limited, if any, support. Friends and family were described as "someone to talk to" but were often limited in their ability to help with care. In other cases, parents/carers described themselves as "loners" or reported that they had gradually lost touch with work colleagues or community groups as the stress of caring for a child with disability took its toll. These findings are consistent with earlier research undertaken in South Australia, which found that social isolation was a risk factor for placement of children with intellectual disability in out-of-home care (Kelly et al. 1995).

Some participants also reported challenges in the education system experience. Several children had attended multiple schools, and parents/carers reported being called to the school frequently as staff were unable to cope with the child's behaviour. Six of the families reported that their child was "suspended for everything" or "constantly suspended and excluded" and parents/carers felt that schools were often not providing appropriate support for their child, believing they were under-resourced and unable to do so. For many families, repeat suspensions from school eroded the few hours of respite that parents/carers relied on:

"Suspensions meant that the child is home all the time and this can be the last straw for some families already living in a very fragile system. They rely on that time from 9am to 3.30pm for respite" (staff focus group/interview 2).

Research in Victoria confirms that schools and other formal services may contribute to the decision of families to place their child in out-of-home care when families are left without a break from caring (VEOHRC 2012).

The experiences and consequences for children with disability and their families following out-of-home care placement

Experiences and consequences for children with disability

Positive consequences and experiences were generally the result of a suitable long-term and stable placement. For many children, their current placement was not their first: often, children had experienced one or more previous placements that had not resulted in good outcomes. Although previous research involving children under the Guardianship of the Minister concluded that improved outcomes are generally present for children in more stable care (Delfabbro et al. 2007), it is acknowledged that not all placement changes are undesirable and it may be in the child's best interests to move if their new placement will be more appropriate (Office of the Guardian for Children and Young People 2013).

Accommodation services' managers reported that children responded well to set boundaries and developed increased levels of trust and respect for themselves and others. Managers also reported that many children had developed responsibility and independent living skills, set goals and had plans for the future. They also observed that "difficult behaviours" began to diminish.

Parents/carers confirmed this, with several declaring that their child had matured and that there had been improvements in their behaviour, medication and sleep management. They also commented on their children being "happy", experiencing better quality family relationships, and being able to "do things as a family" again.

"I didn't know what to expect when [child] went into care, but I never expected [him/her] to do as well as [he/she] is doing now, which is the best in [his/her] whole life" (Parent/carer interview 5).

One of the four young people interviewed experienced positive consequences. He/she mentioned the freedom and independence that out-of-home care offered. Two other young people referred to the range of activities on offer which they were able to participate in.

Some of the staff comments suggested negative outcomes for children/young people, including feelings of grief, loss and rejection; lack of understanding regarding their new situation; arrested development; and a sense of uncertainty. Staff also observed that there was a period of adjustment for all children when they were first placed in care, and that challenging behaviour could escalate if not managed adequately.

Parents/carers from six families spoke of similar concerns for their children. These included ongoing issues with behaviour, or the development of new challenging behaviours; a perception that their child had lost skills; and children experiencing a sense of rejection. Three parents/carers mentioned serious concerns relating to the management of mental and physical health problems, reported suicide attempts and self-harming behaviour. Similar negative outcomes regarding quality of life for children with disability in out-of-home care have been previously documented (VEOHRC 2012).

Three of the young people (n = 4) spoke of their dislike of the rules they were expected to follow and missing aspects of home, such as their pet. One young person made reference to feeling “miserable”, socially isolated and inferior: “I felt like I was less than human, inferior in every way”.

It is important to emphasise that many factors contribute to outcomes for these children; out-of-home care is only one element in a complicated narrative. Behaviours such as those described above are not limited to children in care. Young people with disabilities have poorer mental health and are more vulnerable to developing mental health conditions compared with young people in the general population (Australian Bureau of Statistics 2008; Kariuki et al. 2011); the potential contribution of pre-existing psychological distress to young people’s emotions and behaviours in care is acknowledged.

Experiences and consequences for families

All parents/carers participants acknowledged that the time immediately following the placement of their child in VOOHC was difficult and challenging. As noted in earlier research focusing on young adults (Nankervis et al. 2011), the most common negative experience for families was feelings of guilt and grief. These feelings tended to diminish over time, with the majority of parents/carers maintaining that as they came to accept their child’s placement, and began to trust the accommodation service with the care of their child, things did improve. However, some families were still coming to terms with their decision, and exhibited a strong sense of grief, loss and depression. Consistent with previous research, feelings of guilt or concern for their child’s welfare were ongoing for some parents/carers (Werner, Edwards & Baum 2009).

The immediate adjustment following placement was also difficult for siblings who often found it hard to deal with the absence of their brother or sister, a finding consistent with research conducted in Victoria (VEOHRC 2012). Some young people experienced bullying at school for having a sibling in care, and worry over whether their parents would “get rid of [me] too”. However, according to earlier research, overall siblings were happier and more settled and families experienced improvements in quality of life (Nankervis et al. 2011).

Parents/carers identified positive consequences for the wellbeing and development of their other children. They reported being able to spend “quality time” with those children and siblings who were more able to relax at home and have friends to visit, and most were able to relate positively with their sibling in out-of-home care.

Positive consequences for families centred upon reduced stress and improved mental health for parents/carers. They reported having more time for themselves and their families and feeling able to return to work. Accommodation services’ staff observed that, as a child settled into their placement, parents would become more relaxed and less stressed.

Parents/carers whose child was in a placement that was causing concern reported fewer positive family outcomes, but still articulated the benefits of not having to address the day-to-day care and behavioural needs of their child. Parents/carers of children who were unsettled in their placement reported poorer long-term outcomes than those whose child had adjusted reasonably well to living in care, and spoke of worry, anger and guilt over their decision.

Families' views on services and other supports

Pre-placement

Parent/carer interviewees identified a number of issues with formal services prior to placement, such as availability; their lack of knowledge about services; their relationship with the service coordinator; and the role of schools.

Many parents/carers reported that services were under-resourced, inconsistent and crisis-driven. Several reported that their request for services had either been denied, or had resulted in placement on a waiting list for so long that they had been forced to go elsewhere. Others commented that many services had been promised but not delivered.

Several families felt that they did not have the knowledge or information about services available to them and did not know where to go for help. This finding confirms previous research, which identifies that parents/carers want comprehensive information, advice and support to help find the most appropriate service, benefits and entitlements for themselves and their families (Redmond & Richardson 2003).

A good relationship with the service co-ordinator was identified as critical. The co-ordinator was seen as responsible for connecting parents with services and for providing information regarding other supports. While some families reported a good relationship, this was not the case for others. In addition, several parents/carers described how frequent and unexplained staff changes prevented any depth of understanding of the family situation, and felt exasperated by negative staff attitudes towards families and a lack of respect. Some felt that staff lacked skills, particularly in crisis situations. Victorian research found that poor relationships between families and services and workforce capacity issues (including skills gaps) are risk factors for out-of-home placement (VEOHRC 2012).

A network of informal support greatly increased the chance of parents/carers being able to care for their child at home. Several of those interviewed reported that they had a close network of family members (particularly grandparents and/or siblings) willing and able to care for their child and provide help around the house, which made a huge difference. Some had also linked up with carer support groups, which were noted as providing help for all members of the family; others cited church and close friends as helping them to manage. Chan and Sigafos (2000) highlight the importance of social support systems for families in alleviating the effects of stress.

For some families, finding the right school and an appropriate support team had been a huge help. The VEOHRC (2012) report highlighted the notion that wellbeing is a shared responsibility, with schools and other formal services providing an important part of the support context for families.

During placement

Families valued effective communication with agencies, with parents/carers reporting feeling “abandoned” if they were not included in discussions concerning their child’s future. A co-ordinated approach ensured that all parties were “on the same wavelength” when it came to needs and goals for the child, as well as ensuring

consistency of boundaries and routine between the accommodation service, home and school. A lack of communication and information sharing was an issue for some, with families expressing frustration that they had to tell their story “over and over again” to different support and allied health workers, medical staff, accommodation staff and other agencies. They felt that there was no central point of contact to co-ordinate information about their child, which could then be passed on to relevant parties.

Consistent with previous research (Frederico, Jackson and Black 2010; Ombudsman Victoria 2010), the best-regarded accommodation services were those that provided some form of developmental assessment for the child, as well as therapeutic intervention. As one parent/carer said:

“I just never would have never ever been able to describe [him/her] in those terms, you know being great, being happy, being more mature, being able to talk to [him/her], being able to have a conversation with [him/her]. I know [he/she’s] a little bit older but I really don’t think that has anything to do with it. It’s the fact that [he/she’s] had that care from the [accommodation service] staff that has really helped [him/her] along because they always are working with [him/her], not just caring for [him/her]” (Parent/carer interview 5).

Parents/carers felt that accommodation services with fully trained staff, able to access on-going development opportunities and supportive behaviour plans, provided an improved experience for the child in their care. However, many raised concerns over the skills and training of staff in accommodation services, similar to those noted in a Victorian parliamentary report (Ombudsman Victoria 2010). In several instances, parents/carers reported that their child’s placement had broken down because staff were unable to manage behaviour. Some commented that their children had “lost skills” since being in out-of-home care and felt that staff were only there to “babysit” rather than to work with the child or provide therapeutic support.

Post-placement

Most significant issues for parents/carers post-placement were the quality of accommodation and support available to their child. All felt strongly that the most important factors for the child’s wellbeing were a stable placement appropriate to their needs, with consistent carers. Options such as home-based placements and independent living arrangements were considered most appropriate for some children, while for others the social aspect of a group placement was regarded as important.

Parents/carers also identified informal supports that had assisted them to cope after their child had been placed in care. These included carer and sibling support groups, family members and advocacy services.

Several parents/carers explained that their child had changed schools whilst living in care. In some cases, they reported that the new school provided a more supportive environment resulting in improvements in the child’s behaviour, mood and engagement.

What supports would have assisted parents to be able to continue to care for their child at home?

Although some parents/carers identified that they would have been able to care for their child at home for longer had they had more support, most indicated that the voluntary placement would still have taken place. Participants identified a number of services and supports that may potentially assist families to continue care for their child:

- An ongoing, well-coordinated, wide-ranging and consistent package of services and supports, tailored to the specific needs of each child

- Regular and planned respite, provided in the context of prevention and early intervention rather than crisis
- Networks of informal supports
- Complementary support from schools and other formal services
- Information to families regarding services for the child, carers and siblings.

Conclusion

The study is an important contribution to the small literature examining the situation of children and young people with disabilities who are placed in out-of-home care. Unlike previous studies it focuses on a specific age group, reflects recent and immediate experience, and specifically excludes children and young people placed in care as a consequence of a court order. The study identifies many challenges facing families and factors contributing to the decision of parents to voluntarily place their children in care. The issues identified by families in the study are consistent with those identified in other research conducted in Australia and internationally, despite differences in the characteristics of the populations studied.

The need for more responsive, individually tailored and better coordinated services and supports to families has emerged as a key message. The recent move to Individualised Funding and rollout of the National Disability Insurance Scheme are in line with this approach, providing opportunities to better respond to the individual needs of children with disability and their families.

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