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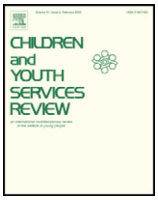

Supporting families: Outcomes of placement in voluntary out-of-home care for children and young people with disabilities and their families

Angela Crettenden *, Annemarie Wright [1], Erin Beilby

Novita Children's Services, 171 Days Road, Regency Park, South Australia 5010, Australia

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ABSTRACT

Parents caring for children and young people with disabilities typically have extensive additional demands on their time and resources. This added pressure can significantly impact well-being and mental health. In extreme circumstances, parents may seek an out-of-home placement for their child. Previous research has looked into factors that influence decisions for families to place their child into out-of-home care but little is known about outcomes for these young people and their families. The Supporting Families study aimed to explore the impact of a voluntary out-of-home placement on young people with disabilities, and consequences for their families. Fourteen parents/carers, twenty six case managers, six accommodation services' managers, and four young people with disabilities participated in face-to-face and telephone interviews and focus groups. Participants reported a range of outcomes for young people in care. Positive outcomes included increased levels of respect for themselves and others, an improvement in independent living skills, and reductions in challenging behaviours. Negative outcomes centred on their experiences of grief, loss and rejection, as well as behavioural problems. Positive and negative outcomes were also found for families. For many parents/carers there was a reduction in perceived stress and caring load, as well as improved mental health and wellbeing for them and the child's siblings. However, parents/carers often experienced ongoing feelings of guilt, grief and loss. The study adds to knowledge about outcomes of being in voluntary out-of-home care for this small but vulnerable group of young people in care and their families.

1. Introduction

Ford, 2007; Bourke-Taylor, Howie, Law, & Pallant, 2012; Singer, 2006), anxiety (Bourke-Taylor et al., 2012), and stress (Harper, Dyches, Harper, Roper, & South, 2013; Hayes & Watson, 2013; Webster, Majnemer, Platt, & Shevell, 2008; Woolfson & Grant, 2006), and to experience higher rates of marital stress (Risdal & Singer, 2004). Children and young people with disabilities have been consistently shown to exhibit higher rates of emotional and behavioural problems than their peers (Dekker, Koot, van der Ende, & Verhulst, 2002; Emerson & Einfeld, 2010; Strømme & Diseth, 2000). This can pose challenges for parents who may be balancing family and work commitments, and are also likely to be experiencing financial pressures (DeRigne, 2012).

In extreme circumstances, parents under duress may voluntarily seek an out-of-home care placement for their child with disabilities

to stay with them for as long as possible and are reluctant to explore placement as an option (Llewellyn et al., 1999; Mirfin-Veitch, Bray, & Ross, 2003). For parents of children with more severe disabilities, particularly those with challenging behaviours, stress accumulates over time. The decision to place is an on-going process, rather than reflecting a single precipitating event (Blacher, 1990; Mirfin-Veitch et al., 2003). The 'tipping point' commonly happens when children reach adolescence and place additional strain on the family unit, with parent concern often focusing on impacts for siblings (Victorian Equal Opportunity & Human Rights Commission, 2012).

The number of children and young people with disabilities who are placed under these circumstances is small in comparison to the number of children in out-of-home care more generally, and disability services may not be well positioned to provide accommodation options. Children and young people are frequently placed for long periods of time in respite care because of the unavailability of other more permanent

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* Corresponding author. Tel.: +61 8 8243 8292.
E-mail addresses: Angela.crettenden@novita.org.au (A. Crettenden), Annemarie.wright@novita.org.au (A. Wright).
[1] Tel.: +61 8 8243 8292.

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options (Nankervis, Rosewarne, & Vassos, 2011a; Victorian Equal Opportunity & Human Rights Commission, 2012). For the purposes of this article, 'respite' refers to the Australian usage of this term. Respite options typically involve out-of-home respite, i.e. where the young person is cared for by paid staff in a facility such as a group home, but may include other options including in-home respite and recreation day or weekend programmes. International definitions of 'respite' and use of terminology may differ. The demarcation of when a child or young person is considered to be 'living out-of-home' rather than perceived to be living at home but with frequent 'respite' is also not standardised across countries.

The term voluntary out-of-home care (VOOHC) is used in this study in preference to the term 'relinquishment', which in this and other studies has been found to be less acceptable to parents (Victorian Equal Opportunity & Human Rights Commission, 2012). Parents who participated in the present study had not relinquished guardianship of their child, nor did they necessarily want to cease playing a part in their child's life. The definition of VOOHC employed in the context of this study is specific to the South Australian Department of Communities and Social Inclusion (DCSI). In this Australian state, a child or young person is classified as being in VOOHC if placement was initiated by their parent(s) or other legal guardian(s) and not subject to a court order, and when the child or young person has been living away from the family home at least two days in the week for a period of not less than three months. Further, children or young people in a VOOHC placement who live in the family home for at least two days in the week are considered to have a 'shared care' arrangement. Readers are asked to interpret study findings in context and to be aware that the meaning of the term VOOHC may differ across Australian states and internationally. In the United States, for example, 'voluntary placement agreements' describe a situation where a parent/guardian is unable to obtain resources to enable them to care for the child in their own home and the Government agrees to provide foster care or places the child with relatives (U.S. Department of Health and Human Services). Some of the young people described in the current study as living in VOOHC with shared care agreements would be termed in England as receiving respite care ('short breaks'), where the child is still thought of as living with their family but with very regular stays away from the family home (Collins et al., 2013).

There has been little research focused on children and young people with disabilities in VOOHC, with most studies exploring factors that may contribute to initial placement (Nankervis, Rosewarne, & Vassos, 2011b; Werner, Edwards, & Baum, 2009). The authors of a review of the existing literature note challenging behaviours, poor coping and lack of support, financial concerns, and carer distress as factors that often lead to placement (Nankervis et al., 2011a). A recent Australian report concluded that the primary driver of placement was unmet need for services, and also noted there to be negative consequences of placement including trauma and grief for all family members and potential family breakdown (Victorian Equal Opportunity & Human Rights Commission, 2012). Other research however has suggested there can be positive emotional changes and improvements in family quality of life and familial relationships following placement, though this may be accompanied by feelings of guilt and worry (Werner et al., 2009).

There is a larger body of research examining the situations of the broader group of children and young people in out-of-home care, with or without disabilities, who are placed as part of the child welfare system. A recent study examining outcomes for children in care suggests they are likely to report that their lives would have been better if they were living with their families (Dunn, Culhane, & Taussig, 2010). Other research suggests this group is also at risk of poorer academic outcomes (Cheung, Lwin, & Jenkins, 2012; Trout, Hagaman, Casey, Reid, & Epstein, 2008) and social exclusion (Jackson & Cameron, 2012). Children and young people with disabilities in a residential group home were found to be even more at risk of social and mental health issues and lower academic performance (Trout et al., 2009). These children are also more likely to have unstable placements than their peers without disabilities, particularly those placed at a younger age (Hill, 2012).

The Supporting Families study was initiated and funded by the South Australian Department for Communities and Social Inclusion (DCSI) responsible for the provision of services to children and adults with developmental and intellectual disabilities. The focus of the study was on children and young people up to 18 years of age with disabilities who were in a VOOHC placement initiated by their parents or legal guardian. This paper will report on a subset of data obtained from the study, focusing on outcomes for children and young people with disabilities and their families, and the VOOHC placement factors which contribute to these. It is acknowledged that the VOOHC placement is only one factor that may impact the experiences of these young people and their families. Feedback was invited from a broad range of stakeholders, including from parents and other legal guardians (e.g. grandparents) of the young people in VOOHC (for brevity this group is hereafter described as parents/carers); case managers, and accommodation service managers. Most importantly, we sought to hear the views of young people themselves, a group that is rarely invited to contribute to research. A variety of approaches were undertaken to ensure participation in the study was accessible to the different participant groups. Parents/carers and young people took part in face-to-face interviews, given the sensitivity of the issues discussed. Case managers attended focus groups to facilitate broad discussion, and accommodation service managers participated in telephone interviews due to their wide geographical distribution, the variation in accommodation services, and the sensitivity of discussion topics for some of the smaller services.

The Supporting Families study was reviewed and approved by the South Australian Families and Communities Research Ethics Committee. Young people provided assent, and parents/carers provided consent for their child's participation. The researchers who undertook the interviews with young people and with parents/carers were also experienced psychologists.

2. Method

2.1. Participants

2.1.1. Parents/carers

Parents/carers of 29 children and young people with disabilities who were clients of DCSI and residing in a voluntary out-of-home placement were eligible to participate in the study. Fourteen parents/carers from ten families agreed to be interviewed (35% of eligible families); seven interviews took place with individual parents/carers and three interviews included two parents/carers from the family.

As the age of the ten young people whose parents/carers were interviewed as part of the study was between 11 and 18 years (median age = 16.5 years), the term 'young people' will be used hereafter to refer to the children and young people in VOOHC who were represented in the study. Seven young people were males and three were females. Six were identified as having an intellectual disability with two having an additional diagnosis of Autism Spectrum Disorder. Four young people had a diagnosis of Autism Spectrum Disorder without intellectual disability. In addition to their primary diagnosis, two young people were also described to have a physical disability (cerebral palsy).

Duration of time placed in VOOHC ranged from 1 year to 9 years (median duration = 1–2 years) with age at placement ranging from 3 to 16 years (median = 15 years). In six cases, the young person had had two or more placements. Three young people were in shared care and the remainder were in full-time VOOHC placements. All young people, with one exception, were in temporary community-based residential care (for the most part group respite facilities) when living away from the family home. Four were being cared for in (or in the process of moving into) an individual placement setting. One young person was living in home based foster care. The remaining young people were living in small group home settings.

Seven young people had primary guardians who were parents and the majority were living in a two parent household before being placed in care. Three young people had primary guardians who were grandparents. In all but three cases, young people had siblings who had been living with them before the VOOHC placement. Eight parents/carers considered their child's placement to be an on-going and permanent arrangement whilst two were unsure about the future. Parents/carers of the three young people with shared care arrangements all expected their child to eventually transition into full-time VOOHC.

The young people represented in the study were largely representative of the population of young people in VOOHC who were clients of DCSI and eligible to take part in the study ($n = 31$). In common with the larger sample: there were more males than females; young people were likely to have a diagnosis of Autism Spectrum Disorder (with or without intellectual disability); and initial VOOHC placement was likely to have happened in midadolescence.

Socioeconomic-status of families in the study was assessed using the Australian Bureau of Statistics Socio-economic Index of relative socioeconomic advantage and disadvantage. This index provides an indication of the social and economic conditions of a neighbourhood area, based on postcode (Australian Bureau of Statistics, 2013). A lower score indicates greater disadvantage. Participants were from across the socioeconomic spectrum (South Australian decile range = 3–9).

2.1.2. Case managers

Case managers who worked with young people with disabilities in VOOHC and their families were invited to participate in a focus group or face-to-face interview. Eligible participants were staff members employed by DCSI. Twenty-six case managers participated in the study, representing a 37% response rate. Participants were from a range of occupations and included social workers, psychologists, and developmental educators.

2.1.3. Accommodation services' managers

Six management staff from non-government providers of accommodation to young people with disabilities took part in a telephone interview; a 75% response rate. All VOOHC placements were funded by DCSI and included emergency respite situations, group home accommodation settings, sole accommodation settings, and home-based care arrangements.

2.1.4. Young people

Four interviews were completed with young people in VOOHC who had a range of disabilities and cognitive capacity. This represents 14% of the 29 young people whose families were invited to participate in the study. The interview methodology used in the study (described below) was not suitable for young people who were non-verbal or who had more severe disabilities (total number unknown to the research team).

2.2. Procedure and measures

2.2.1. Parents/carers

Case managers identified parents/carers of young people aged 18 years and younger on their Voluntary Out-of-Home Care Register. Parents/carers of six young people were excluded from the study due to: the legal guardian being someone other than the parent/carer; parent/carer unavailability; and the parent/carer not having capacity to participate. Letters of invitation were sent to parents/carers of 29 young people in VOOHC.

Parents/carers who agreed to participate in a semi-structured interview ($n = 14$, from ten families) were contacted by a member of the research team to arrange an appointment time. Interviews took place at participants' homes or at another suitable location, and lasted approximately 2–3 h. Topics covered in the interview included characteristics of the young person with disabilities and their family, and outcomes for the young person and family following VOOHC placement. A member of the research team contacted participants by telephone the next day to ensure that they were supported and able to access referral options if required.

2.2.2. Case managers

An email introducing the study was sent to all eligible case managers (i.e. those who had current or previous contact with young people in VOOHC). Two focus groups were held with case managers ($n = 11$ and $n = 6$) and one with senior managers and team leaders ($n = 7$). Discussions lasted approximately 2 h. Face-to-face interviews were conducted with two further staff members who were unable to attend a focus group. Topics covered in the focus groups and interviews were similar to those for the parent/carer interviews, with staff asked to focus on general examples rather than specific cases.

2.2.3. Accommodation services' managers

Case managers identified eight accommodation services (non-government organisations providing accommodation for young people with disabilities placed in VOOHC). The accommodation services were principally providers of respite but also included organisations responsible for home-based care and individual accommodation. Telephone interviews were undertaken with the accommodation managers for six of these services; interviews lasted approximately 45–60 min and covered similar ground to the focus groups.

2.2.4. Young people

Young people with disabilities were recruited through their parents/carers who were given responsibility for deciding whether their child had the cognitive and/or emotional capacity to participate. Interviews took place at the young person's place of residence, Government agency offices, or at the office of the accommodation service, and lasted approximately 1 h.

“Let me tell you…” interview tools were adapted from those developed by Professor Bryony Beresford and colleagues from the University of York (Beresford, Rabiee, & Sloper, 2007). The tools included a ‘social story’, interview schedule and four face paddles. When appropriate, an individualised social story was used by the support worker or staff member from the accommodation service to prepare a young person for the interview.

The interview schedule encouraged discussion about aspects of the young person's life through the use of a facilitatory craft activity (e.g. making a poster), if the young person wished to do so. Questions were intended to encourage discussion about the young persons themselves, their family, living arrangements, and important things in the young person's life. The young people were also asked to describe their aspirations for the future. Participants were given the option of using visual aids as a communication tool, in the form of four face paddles displaying emotions (‘happy’, ‘sad’, ‘angry’, ‘scared’). The tools aimed to assess the emotional wellbeing of the young people, and were developed with the aim of being non-threatening and enjoyable as well as minimising risk of upset by not directly discussing circumstances which led to VOOHC placement. Use of the tools was intended for young people with at least some verbal communication skills.

2.3. Analysis

Field notes from interviews and focus groups were transcribed with reference to audio-tapes of the sessions where necessary. A copy of the transcript of each interview was sent to the participant(s) for validation (with the exception of the young people interviews). Any changes or additions identified by the participant(s) were made prior to data analysis. A researcher who had not participated in any of the interviews then analysed the transcripts for themes at a semantic level (“thematic analysis"), as outlined by Braun and Clarke (Braun & Clarke, 2006). Coding of the data was undertaken in an inductive ("bottom up") way, where themes and sub-themes emerged from the coded data. An on-going process of reviewing, refining, and relating themes to each other was followed and each theme was named and described with agreement from all authors. For the purposes of this paper, individual themes have been collapsed into higher-order categories that are to an extent pre-determined (e.g. positive and negative experiences), but are discussed in text at a more descriptive level.

2.4. Reliability checking

To ensure that coding was undertaken consistently, a second experienced member of the research team independently coded a proportion of participant quotes for the most relevant theme. Initial agreement of 84% was obtained. Discrepancies that were apparent were resolved by discussion amongst the research team.

3. Results and discussion

3.1. Outcomes of voluntary out-of-home care placement or shared care

3.1.1. Outcomes for young people

Positive and negative outcomes were reported for and by young people living in VOOHC. Although the parents/carers who participated in interviews were all in regular contact with their child, information from focus groups indicated this was not the case for all young people in VOOHC; the following data should be interpreted in context. Outcomes for young people who have less contact with their family may be different to those described in this report, as evidenced by previous research into children in out-of-home care (NSW Department of Community Services, 2005).

3.1.1.1. Relationship with family. When asked about their relationship with family, two young people referred to the 'happy' paddle and gave examples of spending time with their family and participating in activities with them. The other two young people indicated that things were not as good; they gave examples of feeing "unwanted" and "inadequate" as well as on-going conflict with siblings and other family members.

3.1.1.2. Positive outcomes for young people. Three of the four young people did not describe positive experiences whilst in their VOOHC placement(s). One young person identified the benefits of freedom and independence. Two others referred only to enjoying the range of activities they were able to participate in at their place of residence. In spite of their reservations around their current living arrangements, when asked about the years to come, all young people were able to think about their future positively. The young people cited a number of goals for themselves in the coming years, such as gaining employment, travelling to a different country, participating in sports activities and clubs, and being in a rock band. Two of the young people indicated an intention to live independently, whilst the other two were unsure where they would be living. Two young people recognised that they will need supports in place to assist them to live the way they would like.

Accommodation services' managers described more positive outcomes for the young people in their care, particularly as they observed the young person beginning to adjust to their new surroundings, get to know the staff, and settle into a routine. Managers reported that young people can respond well to set boundaries and develop increased levels of trust and honesty, as well as respect for themselves and each other. They also felt that many young people learn responsibility and independent living skills, develop goals and ambition for the future, and that "difficult behaviours" can diminish. It was noted by managers that these outcomes generally result from a long-term and stable placement that is suitable for the young person; more negative outcomes were reported in times of uncertainty.

> "If the young person is in a suitable environment then they can change for the better, they blossom, they get good services, and they're happy and have a good quality of life."
>
> [Accommodation service's manager 4]

Although previous research in the field of child protection and involving South Australian children and young people under Guardianship of the Minister concluded that improved outcomes are generally present for those in more stable care (Delfabbro, Jeffreys, Rogers, Wilson, & Borgas, 2007), it is also acknowledged that not all out-of-home care placement changes are undesirable and that 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).

Parents/carers of seven of the young people reported positive outcomes for their child since they had been placed in VOOHC. Several declared that their child had matured since living in care and that there had been improvements in behaviour and medication and sleep management. They also commented on 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]

Echoing the thoughts of other participants, for many of these families their child's current VOOHC placement was not their first. There had often been one or more previous placements that did not result in good outcomes for child or family.

3.1.1.3. Negative outcomes for child. When asked about their living arrangements, three of the four young people used the 'angry' paddle in reference to their current and past VOOHC placements. They spoke of their dislike of rules they were expected to follow and of missing aspects of home, such as their pets. Two young people referred to the 'sad' paddles, and one young person made reference to being "miserable", feeling socially isolated, and feeling inferior: "I felt like I was less than human, inferior in every way".

Case managers and accommodation services' managers discussed a number of negative outcomes for young people in VOOHC, including: experiencing grief, loss and rejection "the child may feel they've done something bad and their family don't want them"; lack of understanding of why they are in that situation and "what's happening to their world"; lack of development "they're not moving forward, they're not learning, not growing, just stagnating"; and a sense of uncertainty "because of the lack of long-term planning they are stuck in limbo". It was observed by most participants in these groups that there was a period of adjustment for all young people when they were first placed in care and that behaviour can escalate if it is not managed appropriately.

Parents/carers from six families reported negative outcomes for their child as a result of being in VOOHC. They spoke of similar concerns, including continuing issues with behaviour or development of new problem behaviours, a perception that their child had lost skills, and their child experiencing a sense of rejection.

> "We do worry about [child], particularly because things aren't going so well for [him/her] with [his/her] behaviour."
>
> [Parent/carer interview 1]

Three parents/carers described more serious concerns for their children relating to the management of mental and physical health problems, including reported suicide attempts and self-injurious behaviour. It is important to emphasise that there are many factors that contribute to outcomes for these young people and that their VOOHC placement is only one element of a complicated narrative. Behaviours such as these are not limited to young people in VOOHC placements. Young people with disabilities have poorer mental health and are more vulnerable to developing mental health conditions than young people in the general population (Australian Bureau of Statistics, 2008; Einfeld et al., 2006; Emerson, Honey, Madden, & Llewellyn, 2009; Kariuki, Honey, Emerson, & Llewellyn, 2011); the potential contribution of pre-existing psychological distress to young people's emotions and behaviours in care is acknowledged.

Serious incidents that highlight extreme vulnerability of these young people were raised by four parents/carers. In all cases, parents/carers indicated they had reported the incident(s) to the relevant child welfare authority and the young person had changed accommodation since the incident or was no longer in contact with the carers in question.

3.1.2. Outcomes for family

Overall, there were more positive consequences reported for families as a result of placing their child in VOOHC than there were for the young people. All parents/carers reported at least some improvement in their own lives and those of the child's siblings, and accommodation services' managers also noted many positive outcomes for families following their child's VOOHC placement. Case managers concentrated more on child outcomes, but did report some adverse consequences for families.

3.1.2.1. Positive outcomes for family. All parents/carers acknowledged that the time following their child's VOOHC placement was difficult and challenging. However, the majority maintained that things became easier as they accepted their child's placement and began to trust the accommodation service with their care. Many parents/carers stated that family life was much improved since their child had been placed in VOOHC. Feelings of guilt or concern for their child's welfare were on-going for some, consistent with previous research (Werner et al., 2009). Parents/carers whose child was in a VOOHC placement that was causing concern reported fewer positive family outcomes, but still articulated the benefits of not having to deal with the day-to-day care and behavioural needs of their child.

Positive outcomes for families were centred on: reduced stress of caring load and improved mental health; time for themselves and their family; and parents/carers feeling able to return to work.

> “As a family, it has been hard having [child] in care, but things have gotten easier after the first year. Although it is not easy to put a child in care, there was nothing else we could do and it's ended up being a good thing big-picture wise for the family.”
>
> (Parent/carer interview 9)

> “My stress levels have reduced significantly. Before it was like living in a war zone. [Child] would target me…you can't restrain [him/her], I had to wear some heavy hitting.”
>
> (Parent/carer interview 1)

> “[I] actually feel that I'm capable at this point of working now. If [case manager] had asked me earlier this year or last year I would have said no because I was so burnt out and exhausted I couldn't have done it…I've brought myself together now.”
>
> (Parent/carer interview 2)

Parents/carers who had other children still living at home mentioned a number of positive outcomes for the wellbeing and development of siblings. Parents reported being able to spend “quality time” with their other children and that siblings were able to ‘have friends over to the house’, relax at home, and to relate positively with their sibling in care.

> “[Child's] placement has done [sibling(s)] a world of good. Now they will have tea with the family and will chat.”
>
> (Parent/carer interview 1)

> “Before [placement] we never had any quality time. Now [sibling(s)] look forward to the weekends so much.”
>
> (Parent/carer interview 10)

Accommodation services' managers commented that as the child settled into VOOHC placement then “parents can become more relaxed as they know their child is safe and in accommodation” and that they “don't look as stressed”. Managers also reported that once the relentless task of day-to-day care was removed, often families were able to better enjoy the time they spent visiting their child or having the child at home:

> “Sometimes you see a huge change and the family become more involved as they don't have to be caring 24/7 so can spend quality time with their child.”.
>
> [Accommodation service's manager 4]

3.1.2.2. Negative outcomes for family. The most common negative outcome for families was an immediate guilt and grief response to placing their child in VOOHC. Parents/carers reported they “had a really hard time”, felt “incredible guilt that we couldn't care for our own child”, and were “lost” as they didn't know what the future held. These feelings tended to become less raw over time, though some families were still coming to terms with their decision and exhibited a strong sense of grief, loss and depression.

> “I couldn't bear to think about it, I felt like I had failed [him/her], felt awful.”
>
> [Parent/carer interview 4]

It also took time for parents/carers to adapt to “having to ring and pre-organise everything” to do with their child, rather than having them at home.

The immediate adjustment was described as being hard for siblings. Parents/carers who had other children living at home reported it was difficult for them to deal with the absence of their sibling, being bullied at school for having a sibling in care, and the worry over whether their parents would “get rid of [me] too”.

Parents/carers whose child was less settled in their placement reported poorer longer-term outcomes for themselves than those whose child had adjusted reasonably well to living in VOOHC. They spoke of worry, anger and guilt: “[child's] treatment while in care makes me think it's the biggest wrong decision…Sometimes I deal with it well, sometimes I just fall in a heap.” The stress of advocating for their child's rights whilst in care and liaising with many agencies to ensure that they had all the services they required was another source of on-going pressure.

Case managers focused on parents/carers' grief and loss, but also on the financial impacts of their child no longer living at home. The loss of the Carer Payment (Government issued financial support to people who are unable to work in substantial paid employment because they provide full-time daily care to someone with a severe disability) reportedly led to financial strain for many families at a time when workers felt they least needed a further stressor in their life. Case managers indicated this was compounded for some families by being charged for their child's “board and lodging” and being required to continue to pay for their child's medical expenses.

3.1.3. Placement factors contributing to outcomes for child and family

A number of VOOHC placement factors were identified as contributing to outcomes for the child and/or their family.

3.1.3.1. Positive factors. Placements that "go well" were felt to be those where the accommodation service recognised the importance of investing in the child, retaining quality staff, and had internal practices and policies that prioritised communication and effective medication management.

Participants from all groups valued the importance of communication, with parents/carers indicating they felt "abandoned" if not included in discussions concerning their child's future. In some instances, the value of a coordinated approach was recognised to ensure that all parties were "on the same wavelength" when it came to the needs and goals of the child, as well as maintaining continuity of boundaries and routine in the accommodation service, at home, and at school. Accommodation services' managers emphasised the importance of regular case reviews and commented that if a child had a case manager who was "very engaged" then this enhanced communication and could significantly improve outcomes for the child.

> "A good case manager can make things happen and make a big difference for the young person as well as for the accommodation service."
>
> [Accommodation service's manager 2]

Participants from all groups felt that accommodation services with trained staff members who were able to access on-going development opportunities and supportive behaviour plans provided an improved experience for the child in their care. Accommodation services' managers highlighted the importance of having supports available to care workers (e.g. "someone at the end of the phone" that they can refer to or ask for advice, as well as counselling support for staff).

Parents/carers who reported positive outcomes for their child also commented on the staff at their child's accommodation service:

> "I trust the workers [at the accommodation service] as I've known them for a long time and I know everyone on staff".
>
> (Parent/carer interview 4)

> "[Accommodation service] has been great for [child] and the staff look after and respond well to [him/her]".
>
> (Parent/carer interview 5)

All groups felt strongly that "long-term respite is not a solution". They reported that one of the most important factors for a child's wellbeing was establishing a stable VOOHC placement that was an appropriate "fit" with the child's needs and had consistent carers in place. Options such as home-based placements and independent living arrangements were thought to be most appropriate for some young people, whilst for others the social aspect of a group placement was regarded as an important component for wellbeing. Consistent with recent findings (Office of the Guardian for Children and Young People, 2013), participants commented that it was sometimes necessary to have one or more changes of VOOHC placement to ensure an appropriate placement fit, but this was believed to be worthwhile.

The best regarded accommodation services were those that provided some form of developmental assessment for the child, as well as therapeutic intervention. This finding is in agreement with previous research (Frederico, Jackson, & Black, 2010; Ombudsman Victoria, 2010). The placement environment was also felt to be crucial, with case managers reporting the best VOOHC placements to be those where the physical setup was appropriate to a child's needs, the child had their own belongings, and meaningful activities were provided. Several accommodation services' mangers felt that because their service provided supports such as an "in-house therapeutic service" or outside activities, they achieved improved outcomes for the young people in their care. Parents/carers agreed on the importance of care staff and a therapeutic approach:

> "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]

The final aspect of the child's place of accommodation recognised as important for a positive outcome was the establishment of routine and boundaries that were consistent for the child across settings. Accommodation services' managers in particular felt that some of the most positive changes they had seen in the young people in their care were a direct result of these methods.

3.1.3.1.1. Negative factors. Limited availability of permanent accommodation for children and young people was thought to be responsible for many of the VOOHC placement elements resulting in a poor outcome. Case managers described the shortage of accommodation and expressed frustration that often they were forced to place a child in accommodation they knew was not able to fully meet their needs because "they have to go somewhere, it's a crisis situation…" They also expressed concern that, in some cases, accommodation agencies may agree to accept a young person when they were not set up to fully meet the needs of that young person. The very limited availability of accommodation also resulted in some young people being placed a considerable distance from their family home, school or community, which parents/carers and case managers felt was not beneficial for child wellbeing.

Accommodation services' managers commented that the number of referrals they receive far exceeds their capacity: "once we're full, we're full". Case managers acknowledged that some accommodation services tried to do "a good job" in the face of increased demand and a substantial increase in pressure on them to provide suitable VOOHC placements.

A repeated cause of frustration for accommodation services' managers was that young people arrived in their care with little or no handover information or personal belongings. The crisis-driven nature of VOOHC placement is such that there is not time for planning or preparation before the child's initial arrival at their accommodation. In many cases though, accommodation services' managers reported that it took "months" before they received full information about the child or were able to reunite them with personal belongings. These participants also expressed concerns that it did not appear to be anybody's responsibility to explain to the child what was happening, and that this caused unnecessary trauma in an already fraught situation.

> "A real problem is the lack of initial information about the young person provided to the support agency so the service will get kids without full knowledge of their behaviour and their individual issues. [We] might find out two months down the track that they shouldn't have been doing something because the child has a particular mental health issue."
>
> [Accommodation service's manager 2]

Families expressed frustration that they had to tell their story "over and over again", to different case managers, medical staff, accommodation staff, and other agencies. They highlighted a perception of no central point of contact to coordinate information about their child which could then be passed on to relevant parties.

In cases where there was a coordinated approach with long term planning and regular case reviews for the child, outcomes were generally positive. However, in many occasions case managers reported that so-called “emergency transition arrangements” could last for a year or more and that ambiguity concerning length of VOOHC placement prevented case managers and accommodation services' managers from implementing a therapeutic and developmental plan for the child: “How do you go about activating a stable environment if you know it won't be stable?”

> “It is difficult for the [accommodation services] to be able to do long-term planning as no guarantee that the child will still be there. Because some placements are deemed as interim and only funded on a three month basis, in fairness to some agencies it's very difficult to do planning around that.”
>
> [Participant in case managers' focus group/interview 2]

Many parents/carers also reported that the contract for their child's VOOHC placement at the accommodation service was only short-term (e.g. for three months) and they often had to go through a renewal process. Such contracts were an on-going source of stress for parents/carers, with several reporting worry that “it could all be taken away”.

In addition to the uncertainty of a temporary VOOHC placement that may last for years, case managers also highlighted that young people were often moved from house to house within an accommodation service, sometimes without prior warning. This could cause considerable disruption to the young person, often exhibited in terms of increased behaviours of concern. Interruption to routine, whether in terms of moving house, moving bedrooms, staff changes, or the transient mix of clients in a respite placement was not considered optimal for a young person.

Many parents/carers spoke of their child's previous VOOHC placements where they had been living with an inappropriate mix of clients. For some young people this meant that they learnt additional behaviours of concern from other residents, whilst for others their independence was constrained by security precautions in place for more dependent or disruptive clients. Parents/carers and case managers also gave examples of young people being accommodated in alternative temporary accommodation and in respite houses where they had to move beds every week when other young people came in for respite: “The combination of accommodation plus respite is not a good concept.”

Many parents/carers and case managers raised concerns over the training and attitude of the carers in the accommodation service, concerns that were similarly raised in a Victorian parliamentary report (Ombudsman Victoria, 2010). They felt that staff members were not trained in disability or behaviour management, had very limited medical knowledge, did not speak English, and considered their work to be “just a shift”. In several instances parents/carers reported that their child's VOOHC placement had broken down because staff were unable to manage their behaviour and “didn't know what they were taking on”.

Case managers and parents/carers reported that accommodation services were unable to provide young people with training to increase their skills and independence because staff members were not trained in a developmental framework. Some parents/carers commented that their children had “lost skills” since being in VOOHC and felt that staff were only there to “babysit” rather than working with the young person or providing therapeutic support.

> “[Accommodation service] staff can provide basic day to day care but that's not what gives children a home.”
>
> [Participant in case managers' focus group/interview 3]

4. Conclusions

The Supporting Families study was undertaken in the context of increasing recognition of the need to acknowledge and provide better support for South Australian young people with disabilities placed in voluntary out-of-home care (VOOHC). This is a small but very vulnerable group whose needs are significant and who require considerable support from services. Whilst several authors have considered the factors that lead to VOOHC placement, this paper adds new information to the limited knowledge base regarding outcomes of VOOHC placement for young people with disabilities, as well as consequences for families. The study was enthusiastically supported by parents/carers, case managers, and accommodation services managers, and all participants were eager to share their experiences.

It is emphasised that many factors impact on outcomes for these young people, and that VOOHC placement is one aspect of a complex and complicated situation. The results of this paper do not take into account circumstances such as the reason for placement, existing mental health conditions of young people or families, or other confounding circumstances that may impact on outcomes. The results are also reflective of the period of time in which the study was undertaken; circumstances for young people with disabilities in VOOHC may have changed since this paper was written and the study does not take into account recent changes in service provision in South Australia. Further, substantial reform of the Australian disability support system commenced in 2013 with the rolling introduction of the National Disability Insurance Scheme (a self-managed model of care). This change has the potential to have enormous impact on the experiences of young people with disabilities and their families, particularly for service provision whilst the child or young person remains in the family home. Future research and evaluation of this change in service model with respect to the number of young people in VOOHC and the outcomes for this group should provide a greater understanding of the role of respite and support services for this group.

Many of the young people in this study had multiple conditions (particularly in the autism spectrum) and extremely challenging behaviours. Participants portrayed circumstances that were mixed and complicated, dependant on time since VOOHC placement and the suitability of the child's accommodation. The placement process is difficult for all involved, but it appears that for parents/carers stress is reduced in the longer term, despite on-going feelings of guilt and anxiety. Similar to the findings of Werner et al. (2009), parents/carers in this study acknowledged their more negative emotions but also expressed feelings of improved wellbeing and increased ability to participate in family and other activities, such as returning to paid employment. The anecdotal reports of resultant benefits to siblings should be explored in future studies.

Participant groups portrayed differing assessments of outcomes for young people with disabilities in VOOHC; although reasons for this are unclear, placement stability, suitability of accommodation, and open communication networks were important in cases where outcomes were positive. There was significant concern from all groups about the lack of stable VOOHC placements and limited good quality accommodation service options, particularly those that could offer developmental assessments, a therapeutic environment or appropriate behavioural support.

The study is, to the best of the authors' knowledge, the first to seek the views of young people with disabilities in VOOHC. The “Let me tell you…” tools proved to be broadly useful for young people of different levels of cognitive capacity, and were able to provide a global picture of well-being. Results raise important concerns of how these young people view their quality of life and suggest more to be learnt in terms of the importance of involving this group in research. Further work should seek to explore the views of a larger number of young people in this situation and to examine more closely the differences in outcomes for young people and their families.

A limitation of the study is its cross-sectional design, which points to the need for longitudinal evaluation of outcomes for this population. It is not known if participants in the Supporting Families study were representative of all families of young people with disabilities in VOOHC, or of the staff who work with and support them. As well, the study cannot be generalised to the broader group of young people with disabilities in care. Very little is known about the specific situations of young people with disabilities whose parents no longer have guardianship; this is an important area of further enquiry as this group could experience very different service provision and community supports and expectations from that discussed in this paper. Nevertheless, results of the study point to factors and possible solutions that have the potential to improve outcomes for all children and young people with disabilities in care and their families. Results also highlight the need for further research directed to understanding relationships between parents/carers, siblings, and young people in care, and the supports they need.

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