



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



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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.

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1. Introduction

Parents caring for children and young people with disabilities may have extensive additional demands on their time and resources and have been found to be at risk of depression (Bailey, Golden, Roberts, & 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 (Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999). This decision is often “heartbreaking” (Victorian Equal Opportunity & Human Rights Commission, 2012, p. 6). Most families want the 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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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

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