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The experiences of disabled young people living away from home under Sections 141 and 142 of the Children, Young Persons, and Their Families Act 1989

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December 2015

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Acknowledgements

We would like to express sincere thanks to the young people who contributed to this research. We acknowledge how difficult it can be to talk about aspects of their lives and appreciate their willingness to do so. We also wish to thank the families and support people who assisted some of the young people to take part in this research. We acknowledge the work ‘behind the scenes’ undertaken by a number of disability support services who assisted with the recruitment of participants.

We acknowledge the significant support received from Harriet Toa during the conduct of the research. Harriet provided invaluable assistance throughout all phases of the work, including during the preparation of the final report.

Finally, we would like to thank the Disabled Children Project Team, and the Ministry of Social Development for sponsoring this research, and the Ministry of Health for leading the recruitment process.

Executive Summary

This report documents the findings of a small qualitative research project commissioned by the New Zealand Ministry of Social Development as a contribution to the Disabled Children: Voluntary Out-of-home Placement Review.

A number of submitters to the 2011 Green Paper for Vulnerable Children, and to the Select Committee considering the 2013 Vulnerable Children Bill, regarded sections 141 and 142 of the Children, Young Persons, and Their Families Act 1989 as outdated, discriminatory and inconsistent with United Nations Conventions and best practice. The Disabled Children Project was subsequently set up in February 2014 to review the leglisation. The review is a specific action (priority 6(d)) in the New Zealand Disability Action Plan 2014-18. The research utilised an interpretive phenomenological approach to analyse the data and to draw conclusions from the findings.

Eight young people who had lived out-of-home through a Section 141 placement agreement were interviewed for the project. All were aged between 17 and 30 years. Section 141 of the Children, Young Persons, and Their Families Act 1989 sets out the statutory process that provides for a family to request a voluntary out-of-home placement of their disabled child. Various processes precede the final decision for out-of-home placement, and for all children so placed there must be agreement through a family group conference that this is best for the child.

When the young person is 17 years of age, Section 141 agreements expire. However, all eight of the young people interviewed remained with the service or, in the one case, family that had been providing support to them up until that age. They were at varying levels of independence, however common to all was at least some support for daily living, including money management and access to activities or employment. None had full time employment. Significantly, the relationship that appeared to be most important to the majority of those interviewed was that with their family.

Three primary themes resulted from analysis of the data that related to the time that the young person was under a Section 141. “Moving into care”, the first theme, illustrated a general lack of understanding, and/or ability to remember why they had moved from their family home. From what could be ascertained, it seemed that the move was associated with an event or series of events that left the family unable to support them. Few suggested anything other than acceptance of the move, with just one person noting concern about what was happening and feelings of powerlessness related to having any choice.

The second theme, “experience of living out-of-home” was broken into two subthemes. The first subtheme, “settling in”, drew on the participants memories of how they felt and the advantages or challenges that they saw in the move. Some young people recalled homesickness, however, most remember being quite happy with where they were. For those that moved to a residential school, there were

friends and a wider range of activities available. All, except the young person who lived with a foster family, experienced a number of moves around different houses within the service. For some this seemed to relate to the first year or two and then they were settled. Others appeared to move frequently and continued to do so after the Section 141 agreement no longer applied to them. The second subtheme, "remaining part of the family", illustrated that for nearly all the participants their family stayed involved and had regular communication with them. Family provided a consistent, meaningful relationship when other adults in their lives, such as their service support people, changed with each move.

The third and final theme "transitioning from Section 141" drew on the young people's memory of knowledge that their status changed at 17 years of age and support that was made available to them at the time. In effect, none really understood the implications of Section 141 no longer applying to them. Because the Education Act provides for young people to remain at school until the age of 21 years, most transition planning was focused on the move from school to adult life. Choices that the young people expressed in relation to transition were related to the types of work they wanted to do and facilitation of their further development towards independence. One young person believed that there was no plan in place for him to gain greater independence from his service. This is of concern given the researchers' perception that he already demonstrated greater independence than others who were interviewed for the research. A conclusion from the data that contributed to this theme is that once the young person entered a support service it appeared they became dependent on that service.

Whilst this is a small study there are some key messages that can be taken from the data that the young people shared.

Firstly, there should be independent advocacy available throughout the years that young people are under Section 141 and in the transition phase. An independent advocate might assist the young person to have a voice outside of the service. The appropriately qualified person could also assess the young person's situation and ensure that they were getting the best possible support.

Secondly, all young people should have a clear transition plan prior to age 17 years. That plan needs to be done with the young person and include helping them to understand, within their capacity, their rights according to the UNCPRD and the relevant laws in New Zealand. An awareness of the developmental needs of the young person should also be taken into account and steps taken to ensure that they have available to them appropriate educational opportunities into their adult years.

Thirdly, positive family relationships are important. While most young people in this study identified that their family relationships were intact, the emphasis that they placed on these relationships indicates the value of services and families working together to strengthen and, when necessary, recover family engagement. Furthermore, it brings into question whether the need for young people to go into out-of-home care might be better addressed through earlier intervention with families. It is possible that some of the young people interviewed might not have come under Section 141 agreement had their family received support appropriate to their need.

Introduction

This report is based on research commissioned by the Ministry of Social Development, and was specifically designed to contribute to the Disabled Children Project set up by the Ministries of Social Development and Health in February 2014 to carry out the Disabled Children: Voluntary Out-of-home Placement Review.

Essentially this review related to disabled children placed in out-of-home care under an agreement made pursuant to Sections 141 or 142 of the Children, Young Persons, and Their Families Act 1989 (hereafter referred to as “the Act”). A range of interested parties were encouraged to participate in public consultation activities, however, this method was not successful at gaining feedback from young people who had experienced an out-of-home placement made under a Section 141 or 142 agreement at the request of their parents. In recognition of the importance of hearing from these young adults, a separate process for consultation with them was initiated. Specifically the Donald Beasley Institute, an independent research institute that specialises in disability research, was contracted to develop and conduct qualitative research with young people who had previously been in Section 141 or 142 placements. The findings of the research are the focus of this document. The research is narrow in scope, focusing solely on the expressed experiences and views of young people aged between 17 and 30 years who were previously subject to Section 141 of the Act.

Background

Sections 141 and 142 of the Act make provision for out-of-home care of disabled children through the Ministry of Health’s Disability Support Service (DSS). Section 141 refers to placement of disabled children within organisations that have been approved as a Child and Family Support Service, whereas Section 142 allows for children to be placed with a residential disability care operator which can include adult residential services. The choice of placement is guided by the Needs Assessment and Service Coordination (NASC) process, which determines the child’s needs. Final approval of agreements under Section 141 and 142 are via a Family Group Conference coordinated by Child, Youth and Family (CYF). Prior to accepting out-of-home placement the participants in the Family Group Conference must be satisfied that, even with all the support and services available, the parents cannot provide care for their child at home. While there is an expectation that placements are reviewed annually, there is no limit to the number of times that the agreement for out-of-home placement can be renewed. Thus, children might remain under a Section 141 or 142 agreement until their 17th birthday, when they are no longer covered by the Act.

It is important to note that unlike other children placed in care under the wider umbrella of the Act, disabled children under Sections 141 and 142 agreements are not supported by CYF social workers. Interestingly, the 2015 report from the Office of The Children's Commissioner (2015) highlighted a lack of information about outcomes for children in care in New Zealand despite the oversight of CYF social workers. For the majority of New Zealand children who enter care under mainstream provisions of the CYPF Act, oversight of their placements continues to be the responsibility of the CYF service. In contrast, for children who come under Section 141 or 142 of the Act, it is the Ministry of Health (which has responsibility for funding and auditing services) that might provide some general oversight. Whilst the focus of the Children's Commissioner's report was on CYF's responsibility to children in their care, the report noted the need for CYF to work with other agencies, including the Ministry of Health, to ensure that all children who come under statutory care arrangements are getting the best support possible. The report was sobering reading, acknowledging that the limited information that was available did not provide reassurance that children were better off after they came into State care, indeed, there was some indication that they were not.

Clearly the review of the legislation for out-of-home placements for disabled children that provided the impetus for this research predates the Commissioner's report, however the report does highlight and affirm the importance of this work. Furthermore, The New Zealand Disability Action Plan 2014-2018 (MSD, n.d.) states a number of priority areas for advancing the United Nations Convention on the Rights of Persons with Disability (UNCPRD) and the New Zealand Disability Strategy (NZDS). Amongst the priorities (6, section d) was the need to:

> *"review care and support processes for disabled children who are (or likely to be) subject to care under [the Act] to establish whether they are being treated equitably and fairly, and in their best interests, and if not, to provide advice on changes needed to legislation, operational policy, operational delivery and/or monitoring and enforcement."*

Key components of the UNCRPD document ("United Nations Convention on the Rights of Persons with Disabilities," n.d.) that inform the above priority include the following:

- Preamble R notes a requirement to ensure that children with disabilities "should have the full enjoyment of all human rights and fundamental freedoms on an equal basis with other children".
- Article 7 notes that "in all actions concerning children with disabilities, the best interests of the child shall be the primary consideration" and "children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, and on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right".
- Article 23 states that parties are to "prevent concealment, abandonment, neglect and segregation of children with disabilities" and that "a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such a separation is necessary for the parents on the basis of disability of either the child or one or both parents".

The voices and views of young people

The consultation undertaken by the Disabled Children Project to date has been with interested parties such as families, children's advocacy organisations, and disability support services to determine the extent to which children coming under Sections 141 and 142 are being treated equitably and fairly, with their best interests central to decision making. However, whilst these other parties have important viewpoints, it is critical to hear from the disabled people who have experienced such out-of-home placements. Data collated for the report, "State of Care, 2015" (Office of the Children's Commissioner, 2015), included either interviews or focus group findings from young people who were currently in the care of CYFs. Four themes were identified from this data. These were: "Tell us what to expect and what we are entitled to"; "Provide us with high quality caregivers and social workers"; "Support us to maintain positive relationships with our birth family/whānau"; "Give us a voice in decisions about our own care, and listen to what we say". Although the young people could identify positive examples of these themes, it was notable that many negative experiences were reported. Referencing these findings against the recorded complaints, of which there were few, led the team to surmise that children within the system might not find the formal complaint system accessible. Having a sense that a complaint is going to be taken seriously is also important, and as Abbott, Morris and Ward (2001) discovered in their research with disabled children living away from home, young people's experience can be that complaints are not resolved to their satisfaction.

A second report that included the experience of New Zealand youth who have lived away from home identified frequent changes in living arrangements, schools and the people who were supporting them (Stevens, Munford, Sanders, Liebenberg, & Ungar, 2014). The young people in this study were involved with multiple youth services, usually as a result of their behaviour or having been subject to neglect or abuse. For most of these young people, despite ongoing difficulties and tensions, parents remained their most constant relationship. The authors concluded that well supported long term relationships, either with family or in the absence of family another skilled adult, led to greater resilience and better outcomes for the young people. Both these findings and those in the recent Commissioner's report raise the question as to whether the experience of disabled children in out-of-home care in New Zealand is any different to that of their non-disabled peers.

Disabled children's perspectives on out-of-home care

There are only a small number of studies that specifically explore the experiences of disabled young people in care. Additionally, caution is required in interpreting the international literature on disabled children and out-of-home care as it does not always differentiate between those children who continue to live with their parents for a significant number of days each year but also spend time in other living environments and arrangements, and those who are permanently living out-of-home. In their review of the literature on "looked after" children, Dowling, Kelly and Winter (2012) included children who were out-of-home for more than 90 days each year. From the studies included in their review, Dowling et al. identified that the pathway to becoming a "looked after" child was complex, including stress within the family and incidents of abuse or neglect. Whereas stress within the family might result in voluntary placements, such as with Section 141 in New Zealand, a concerning finding was that many of the neglected or abused children within the United Kingdom were also in voluntary placement rather than subject to a Care Order.

A further consideration in reviewing the literature is the type of impairment that the child has. For example, whilst Dowling et al. (2012) found some studies on the perceptions of children in out-of-home care, the data was very limited when it came to children with learning disability. The largest single impairment group were young people requiring support for their mental health, suggesting that their out-of-home care might be related to an intermittent health concern for which specialist treatment was required. Perhaps the most significant study of young disabled people's perceptions of living away from home was the work done in the United Kingdom in the late 1990s (Abbott et al., 2001). Whilst this research included disabled children with a range of impairments, the authors did include children with learning disability who had placements in residential schools. It should be noted that Dowling et al. did include this research within their review, thus it is one of the few as stated above. For the purpose of the current study into the experience of New Zealand children who come under Section 141 it is useful to expand on the findings of the Abbott et al. work.

A total of 32 young people contributed to this research, however for 18 of these young people their participation was through a second party (for example, support person or teacher) and observations from the researcher (Abbott et al., 2001). The remaining young people participated in an interview. Most of the young people had moved to residential school before the age of 11 years and had limited say in the decision to move out of home. Whilst some saw the move as in their best interest, most would rather have remained at home.

Of those who could express their feelings, homesickness was common after they first entered the residential school. Observations of support staff suggested that the other young people were similarly affected, commenting on individual's sadness that would be replaced with happiness after talking with family. Although their separation from family was challenging, it would seem that the school community did provide the opportunity for more friendships than the young people had experienced at their previous schools. However, there were mixed emotions in that these friendships, while important at school, were not necessarily available either during holidays at home or after the young people left the residential school.

There were two major approaches to the time periods that the young people were resident at the school. Which approach was taken appeared to be related to the young person's impairment or behavioural challenges measured against the family's context and their coping skills. School terms defined the time of residence for many of the young people, meaning that they went home for holidays, much like a typical boarding school arrangement. For others it was more common to go home for weekends but remain resident throughout the school term and holiday periods aside from these brief home visits. Whichever approach most young people enjoyed going home, although some expressed boredom due to lack of friends and activities during the longer holiday periods.

Boredom, however, was not confined to holidays, with some young people getting bored during after school hours at their residential placement. The authors noted variability between schools in relation to activities on offer outside school hours, with young people commenting on liking their options, some seeing few options and others suggesting that they needed fewer activities after a school day due to feeling tired. Whilst not with children who lived out of home, the importance of having something to do is reiterated by disabled Australian children interviewed about their wellbeing (Foley et al., 2012).

In addition to the peer relationships developed at school, for some young people there was the opportunity to develop strong relationships with their key worker (Abbott et al., 2001). However, whilst some reported that they had close relationships that they valued, others were less positive. For the young people unable to verbalise their feelings about their relationship with their support person, the researchers' noted observations of interactions. Essentially their observations supported the comments from the other young people as they noted both responsive, respectful and unresponsive, disrespectful support people.

Other literature that conveys the opinions of young people who have lived away from home can be found in various sources. For example, in reporting on their advocacy group, the Chailey Young People's Group with Sue Virgo (1998) drew on their group membership to identify comparisons between living at home and living at the school. For a number of these young people school provided greater autonomy in everyday decision-making, such as what they wore and staff were seen as less "bossy" than their parents. Most, however, also talked of missing home, including parents and siblings, but, as with Abbott et al. (2001), residential schools provided an opportunity to develop friendships with peers. Being able to ask for the things that they wanted at Chailey was more difficult than at home and, as highlighted in both the State of Care document (Office of the Children's Commissioner, 2015) and Abbott et al. (2001), such difficulty extended to being listened to and taken seriously.

Further support of the above comments from disabled young people can be found in other research. Turner (2003) reported on the views of young disabled people from Wales, who also expressed frustration at not being listened to. Whilst these young people were living at home, they were consumers of various services and commented that many of these services fell short when it came to hearing their opinion or expressed need. The importance of peers and friends is again reinforced in this study, as is the mixed emotions when spending time away from home. The struggle to fit in that is inferred through much of the research was supported in this study as the young people expressed feeling more comfortable when sharing leisure activities with other disabled youth.

Foley et al (2012) captured the views of twenty children aged between 8 and 16 years, most of whom had an intellectual disability. In asking about what contributed to their sense of wellbeing the children identified relationships with friends and family and feeling good about themselves. Meeting their own academic expectations was a challenge for these children, with the authors commenting on the need to manage inclusion so that children can benefit from being with peers while not losing self-esteem when their academic achievement did not match others in their class. Interestingly, academic challenges were not a feature of the residential school research, suggesting that those children might be less exposed to competition for academic success.

In conclusion, whilst there is not a lot of research, and the views have generally come from young people living in either the United Kingdom or Australia, the findings of these studies share a number of features. Key points include missing family while enjoying the increased peer contact; living away from home might provide greater autonomy in small decisions (for example, clothes) but it can be more difficult to express other desires and be taken seriously; some but not all settings are responsive to the individual needs of the young people they support.

Involving young disabled people in research

There is a growing body of research that has sought the views of young disabled people. Whilst the topic of the research might vary, these studies demonstrate a willingness to listen, value and learn from the young people's experience. It has been suggested that studies about the childhood of disabled children should begin from a position of valuing all childhoods (Curran & Runswick-Cole, 2014). In doing so, the focus shifts from the child's impairment to one where inquiry is centred on their voice and experience from the position of their embodied identity.

Whilst the children's voice becomes central to such research, there are a number of challenges. Perhaps the most obvious are the variations in disabled children's ability to express their thoughts. Utilising more than one approach to data collection is a common strategy that aims to address communication challenges (Connors & Stalker, 2003; Dowling et al., 2012; Preece & Jordan, 2010; Turner, 2003). To enable multiple approaches, studies generally have reasonably long periods of planning and often multiple visits with the young people. For example, Turner notes the importance of having a range of creative strategies for exploring the young people's experience and that to ensure these are appropriate it is necessary to involve a small group of young disabled people in their development. In their book, Connors and Stalker share some of the tools that they used to assist those who needed extra support to respond to their questions, noting that they, too, reviewed the appropriateness of these tools with two young advisors. Connors and Stalker also encouraged the young interviewees to prepare for their interviews by gathering together items or documenting, through drawings, recordings or writing, things that were important to them. In addition, their research was not restricted by the young person's mode of communication, with British Sign Language, Makaton and facilitated communication all being used as needed.

Specific impairments might be more readily identifiable as likely to have an impact on the young person's ability to participate meaningfully. The particular challenges of including young people with Autism Spectrum Disorder (ASD) are highlighted in the interviews conducted by Preece and Jordan (Preece & Jordan, 2010). Single word responses, repeating questions back (echolalia), providing concrete lists of likes and dislikes, being focused on one thing, were all evident throughout their interviews. In addition, the young people's level of anxiety and/or their difficulties with social interaction meant that they found it difficult to concentrate on questions and would move around the room or seek out a familiar person for comfort or to assist them with answering. Responding to these young people required sensitive interviewers who could recognise when to withdraw. Furthermore, allowing time for the young person to become familiar with their presence is a consideration when planning the research.

When working with disabled young people in research contexts, a range of ethical issues must be acknowledged and addressed. As Curran and Runswick-Cole (2014) suggest, ethics can be “messy, complex and challenging” (p.1625) when considering research with disabled young people. At all steps of the research process there are ethical considerations not least when it comes to how the researcher conducts themselves throughout data collection, analysis and reporting of the results. Ideally, a participatory approach to each of these steps would be taken, whereby the young people are not only involved in the development of data collection tools but also contribute to the analysis, with their voice clearly evident in reports. However, such a level of participation further adds to the time taken to conduct and report on the research (Conder, Milner, & Mirfin-Veitch, 2011).

Methodology and Method

As previously mentioned, this report is focused on a small, descriptive, qualitative study that was developed in response to the Ministry of Social Development’s review of Sections 141 and 142 of the CYF Act as part of the Disabled Children Project. Interpretation of the data collected was guided by Interpretive Phenomenological Analysis, which prioritises interpretations held by individual participants but also allows the analyst to develop a deeper understanding based on their knowledge of data collected across the wider sample group (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). This analytical approach was assessed as relevant to the participant group as it enables the researchers to use individual experiences to build a more comprehensive understanding of particular phenomenon.

Aim

The aim of this research, which was agreed with the Disabled Children Project team, was specifically to gather and analyse the views of young disabled adults who have recently exited a section 141 or 142 CYF Act out-of-home placement agreement. The findings were intended to inform the work of the Disabled Children Project. In collecting the perceptions of the young people, it was anticipated that the findings would facilitate participation of disabled young people in the development of the legislation, and policies and practices that are more appropriate for and responsive to disabled children.

Ethics

A full ethical proposal for the research was developed and submitted to the Ministry of Health, Health and Disability Ethics Committee. The Central Health and Disability Ethics Committee approved the study (Reference: 15(CEB)111). The following section of the report provides an overview of the research processes implemented in the study.

Recruitment

At the commencement of the research, it was intended that young people who could reasonably be described as recently exiting Section 141 or 142 placements would be included as participants. This age criteria was extended however after we experienced difficulty recruiting participants in the 17-22 age bracket and the decision was made to open it to those aged between 17 and 30. This resulted in greater uptake of the invitation to participate.

Young people (17 – 30 years of age) who had a previous placement under Section 141 or 142 were invited to take part in the research (purposive sampling). The Ministry of Health undertook this aspect of the research as they held the contact details for the young people. The letter of invitation assured potential participants that their details would not be released to the research team unless they indicated their willingness to be contacted by completing a participant interest form. Accompanying the letter of invitation (see appendix 1) sent out by the Ministry of Health was an Information Sheet (see appendix 2) and a Participant Interest Form (see appendix 3). On receipt of a Participant Interest Form the researchers at the Donald Beasley Institute contacted the person and/or their nominated support person and provided any further information that was requested at that time. If the young person agreed, a visit to carry out an interview was arranged. Support people were important in terms of facilitating appointments, with just one young person taking responsibility for meeting with the interviewer.

Both the Information Sheet and Consent form (see appendix 4 and 5) were available in easy read format as well as a format more typically used with ethics processes. The Easy Read formats were developed by People First New Zealand as part of the translation service offered by the organisation. The translations are piloted with people with learning disabilities to ensure their accessibility. The participants were offered a choice of format, with most choosing the easy read version. Consent to take part in the research was determined to be an ongoing process and whilst participants signed their consent at the start of the interviews, the researchers were sensitive to the person's level of engagement and reviewed willingness to continue at various points throughout the interview process. It is also important to note that in anticipation of any disclosure of abuse a responding to abuse protocol was developed (see Appendix 6).

Participants

Eight young people were recruited into the study with a number requesting that their support person be present (see Table 1) on table pseudonym, sex, age, support person present

As part of the inclusion criteria, all needed to have some form of communication available to them due to the expressed aim of hearing the views of young people. Seven provided their data verbally and one used a process of facilitated communication. All were subject to Section 141 of the Act.

Name (pseudonym)	Age Range	Age on Entering Care	Type of Care	Still in Care	Support Person Present	Impairment
Andrew	21-25	14	Residential	Yes	No	ASD
Beatrice[1]	17-20	8	Foster	Yes	Yes	ASD DS
Charles	17-20	12	Residential	Yes	Yes	ASD
David	26-30	9[2]	Residential	Yes	No	DS
Elizabeth	26-30	7[2]	Residential	Yes	No	DS
Frances	21-25	Approx 16[2]	Residential	Yes	No	DS
George	17-20	Approx 13[2]	Residential	Yes	No	ASD
Harry	17-20	16	Residential	Yes	Yes	ASD

Table 1. Participant Demographics

Impairment: All participants had some degree of intellectual impairment.

ASD = Autism Spectrum Disorder; DS = Down Syndrome

[1] The only participant that was non verbal.

[2] Age was not always specified. Some young people might have been under Section 141 before moving to their current service. Age stated here was estimated based on the history that the young people provided.

Data collection

Data was sourced through semi-structured interviews and observations noted by the researchers. Interviews were carried out in both the lower South Island and the lower North Island limiting them to one-off events to fit within the time constraints of the project. The interviews were recorded and key points transcribed. Whilst some interviews produced recordings that were clear and able to be interpreted, a number of interviewees had some difficulty expressing their views due to difficulty remembering and/or being able to find or clearly pronounce the words they wanted. Notes taken by the researcher at the time were essential to understanding their meaning. The researchers drew on a range of strategies to draw out the person's perceptions. On meeting the young person, the researcher took 10 to 15 minutes prior to the consent process to establish rapport. Conversations typically focused on the young person's day thus far and included sharing something of the researcher's day or travel. Following consent, interviews began with the young person's current life in order to orientate them to the interview process with questions that they generally find easy to answer (selected from the Interview Schedule – see appendix 7). As the interview progressed the past was explored, beginning with their memory of coming into care and, if they had any memory of it, the events that preceded their out-of-home placement. Concrete data, such as were they lived, was used to try and draw out how they felt or more esoteric information. Although few took advantage of it, the young people had been invited to bring photos or other mementos to the interview, they were also offered the opportunity to draw or write words. Blank pages of paper were useful in drawing family or community connections. At the end of the interview the researcher again provided an opportunity for more general conversation to ensure that the young person was comfortable and felt valued for sharing their time and information.

For one participant it was the nominated support person who provided information. This young person understood the purpose of the research and provided consent but was unable to provide a detailed verbal account of the experience of living away from home. This young person did however show us a lot of visual (for example, photo book) and other physical examples of their past and current life. In reporting the results of this study, this participant's information has been used to support the general findings where relevant.

Data analysis

A pragmatic approach was taken to data analysis, which was guided by the aim of the study and the subsequent semi-structured interview framework. Utilising an interpretive phenomenological approach (Tuohy et al., 2013) meant examining the data from each individual to draw out the meaning that out of home placement had for him or her. Once individual perceptions were evident, comparisons between individuals led to a deeper level of analysis that could then be integrated with the researchers’ observations noted at the time of the interviews.

Findings

Interviews began with an opportunity for the young people to tell the researcher about their current lives. The purpose of that approach was to encourage them to talk while getting used to the interview setting. The data generated through these initial discussions provide a context of their current lives and have meaning in terms of how moving out of home might have impacted on them in the longer term. For that reason a brief overview of this data is offered by way of introduction to the young people. Following that introduction, data is reported utilising the key time periods of "Moving into care"; "Experience of living out-of-home" and "Transitioning from section 141". For each of these time periods the focus is primarily on the young people's experience and understanding, however integration of information gathered at the time of the interviews have also been included where relevant.

The young people today

An important finding from this research was that all of the participants have remained in care within the same service or family. For one participant, the family that had fostered her over many years had sought, and been awarded, full legal guardian through the Family Court. All seven other participants remained within the service that had supported them when they turned 17 years of age. The level of care they received from their particular service differed, although all were independent to at least some degree. Welfare guardianship in regard to these participants was not explored, however there were aspects of their lives where they did not have total control, money being the most evident. For example, Andrew talked about how the service would give a clothing voucher or allowance to go and buy clothes, sometimes with support but sometimes by himself. Elizabeth noted how she had progressively gained independence with her money, "[support person] says I can look after my own money now…I've got my [names bank] card and my eftpos card…I have to get cash out because we have to stick to our budgeting". In addition, she was saving "To go to [place] next year with my Mum for my 30th".

In terms of living arrangements, only one of the participants lived independently in a flat with another person who was supported by the same service. The service supported them both in many aspects of day-to-day living, with their home displaying some of their needs on pin boards in the kitchen area, both as reminders to the men, and for their support staff. Two women were moving towards more independence, with their service supporting them to learn the necessary skills to manage in a flat. Attention to future living arrangements differed between services as well as for the one participant who lived within her foster family. Beatrice's foster mother was making plans for her future with consideration of her achieving as much independence as possible. The younger men lived in homes within a service in which support staff were present 24 hours a day, however two of these were already planning for a future where they would be more independent. Andrew flatted with a number of other men, with his service providing a sleepover. Although Andrew expressed "I think I'm sort of at the stage where I've gained what I need to gain and it's time to move on but…", his service did not appear to be planning, with him, a shift to a more independent life. Overall, it appeared that most participants lived with people that were of a similar age, however, one participant lived with men much older than him. When questioned he confirmed that he liked this arrangement.

None of the participants were in full time paid employment, however they did identify a range of paid and unpaid work experiences. Paid employment included roles such as car washing, dish washing, cleaning, working at a cheesery, and paper runs. Voluntary roles included helping at a local Op Shop, and at the Aquarium. In addition to their work, all had some one-to-one time with a support person. However, how that time was used differed, with specific life skills the focus for some, while for others it was time to choose an activity that they wanted. Most of the participants had a range of other activities, including dancing, tae kwon do, music, bike riding, weaving, rock climbing, swimming and art. There were varying levels of independence within this. Some of these activities were undertaken within the school setting, others with support out in the community, and others independently.

The ability to choose and have a say is highlighted several times within the interviews, from choice over having someone with them for a doctor's appointment, through to the choice to live within a residential setting. For others, choice came in determining what they would like to be called. Two participants were known by names other than their given names. Some of the other choices that participants had made were around contact with friends and family. For several who reported difficult relationships with specific family members, this meant choosing not to see them as often, while for others this meant having the ability to call family whenever they wanted to.

Relationships with family were important to all the young adults. Most talked about visiting family, or having family visit them, as well as regular phone, Skype or email contact. Facebook was identified as a useful tool by at least one participant, as Harry noted it is the older generation that is still adjusting to technology "Facebook, yes as well […] just my Mum. My Dad doesn't have one.". Many knew family relationships well, providing names, ages, and comments indicating how their families functioned. It was evident that family remained a presence within their lives, with the other major relationships identified by some of the young people being their friends who were supported in the same service and had attended school with them.

Many identified the plans they had for the future, not only in terms of where they wanted to live but what they wanted to do, how they wanted to spend their money, and the people they wanted to be around. For example, Frances hoped to move into a more independent flat in the near future and when asked who with responded, “go flatting with my boyfriend …”. Intimate relationships were identified as important, particularly by older participants. For example, David commented about one young woman that she … “used to be my girlfriend but she dumped me”, however he went on to tell the researcher that he was excited about a disco being run by the service and that he might find another girlfriend there.

Overall, when asked about their current feelings, participants generally replied that they liked where they were now. While many had dreams for the future, they were also content with their current living situation and happy with the support they received. For those who could articulate their level of happiness in some way, responses were generally positive but some did identify that things could be hard sometimes.

Moving into care

Few of the young people related with clarity their understanding of when and why they moved out-of-home. Some tried hard to contribute the scant pieces of information they possessed about their move from home, while others had no memory at all about the events leading to their move. Without the contributions of family, it was difficult to ascertain exactly what led to their family seeking and/or agreeing to a Section 141 out-of-home placement agreement, although there was some evidence that a single event was perceived to be the final catalyst for the move to initiate a formal Section 141 or 142 agreement process. For example, Elizabeth noted that her parent’s separation coincided “… it was about that time I moved to [disability service]”, while Frances’ move happened soon after her father died.

More commonly however there was either direct or indirect evidence in the data that a number of factors came together to initiate the move. While few showed insight into how these factors might have influenced their move out of the family home there were some exceptions. Andrew recognised that his mother, who was primarily parenting him alone, was no longer able to manage his behaviour “Mum copped a lot of it which wasn’t fair on her.” He could also see that there were various influences on his behaviour, including a history of school bullying, the separation of his parents and difficult relationships with his father’s reconstituted family. Elizabeth knew that her mother “… used to struggle lots … she had to work. I do understand that”. Meanwhile Harry’s support person indicated that Harry had initiated the move himself with Harry explaining it was “because I’d been missing my brother so much …”. Harry’s brother had moved to the same service two years before.

It should be noted, however, that whilst some had developed insight or were able to give a reason for their move to the service, their interpretations mostly seemed to be from them piecing information together. For example, Elizabeth reported that the reason had not been explained to her at the time. When George was asked why he lived away from home he turned the question back onto the interviewer by asking “Do you know why I had to live away from home?” He then went on to relate a history of school moves both within the region in which his family lived and to outside regions for special schooling. Frances, too, had been to “heaps of schools” and she suggested that her mother’s living arrangements after her father died might not have been suitable for her.

Most accepted the move to out-of-home placement. The tendency to acquiesce to such arrangements was well illustrated by Charles who recounted that his initial move (age 12) was to a service within one region and then a year later he was told he would move to a different service in a different region. His support person came with him for a few days and then left. In telling this information Charles was matter-of-fact. However, Andrew remembers being less accepting, although ultimately seeing no choice. “I think I just sucked it up …”. The idea that there might have been a different solution to whatever was driving their move out-of-home occurred to none other than Andrew. His memory is of trying to suggest other solutions “I think I did mention it [after school support for his mother] a couple of times but I guess no one thought to act on it or check up on it or…”.

There was limited evidence of people actually choosing where they went. As noted above Harry chose his service. Frances felt that she had a choice about accepting the service, although it is not clear that she was offered other choices. In both of these situations the young person was in their mid teenage years, whereas many of the others entered the service at a younger age. Beatrice, who showed us the story of her life through photos, became subject to a 141 placement aged eight as a result of her family not being able to manage her physical care or respond to her behaviour in a way that was positive and appropriate.

Experience of living out-of-home

For all the young people interviewed there was continuation of their care arrangement beyond the age of 17 years. That made it difficult for them to separate their experiences whilst under Section 141 from those that occurred later in their life. However, the following two themes and their subthemes are, as best as it was possible to identify, related to their years out-of-home while under Section 141. Two subthemes are identified in the theme "experience of living out-of home", these are "settling in" and "remaining part of the family".

Settling in

Moving into a new residence, away from family, inevitably lead to a settling in period. Most of the young people interviewed moved geographical regions as well. A difference between the people interviewed was that the majority moved to a service that provided on-site education, whereas two remained in the school that they were attending while living at home. Thus, most experienced a major change in their day-to-day lives, with no continuity.

Perhaps surprisingly, given the major changes, most of those who could remember expressed being generally happy following their move. David had memories of being happy sometimes but not always, George commented, "It's been alright", whereas Harry was more enthusiastic stating, "I enjoy being here …". Both Frances and Elizabeth felt that the move had been "good" for them, reflecting, perhaps, the preceding events. Andrew found it more challenging as he continued to live near his home but was not allowed contact with his mother for the first couple of weeks. He understands the purpose of the restriction was to "get me used to being in [the disability service] … I guess they were trying to get me to connect with people in the house …".

Amongst the adaptations that the young people could identify was their struggle with homesickness, living with different sets of rules and coping with the behaviour of others. Each of these might have an impact on whether or not the person felt safe in their new environment. Andrew talked of feeling physically safe but "…didn't feel emotionally safe". George found it uncomfortable when his flatmates were "… annoying and have hissy fits …" asked if he felt frightened, however, he responded "No not really". David identified that one of the things he struggled with early on were the rules applied to his challenging behaviours, a similar sentiment came from Harry as he expressed some frustration regarding his pocket money, "I have to use quite a lot of it if I break something …".

Moving away from home did not mean leaving everything behind, with all the young people identifying that they could have things that were meaningful to them in their rooms. Such things included soft toys, books, photographs, cell phones, i-pads and radios. The last three being dependent on how many years ago they were under Section 141. It was observed by the researcher that some younger people had restricted or supervised access to the electronic equipment. Andrew commented on “pamphlets and things” being “either confiscated or removed” and in his case he felt that other people did not want him to take toys. When he left home Harry had his own agenda dictating how much he had in his room “I am able to have some books. I didn’t want to have too much stuff in my room … I’m trying to make sure there is enough room for myself”.

For most of the young people there were advantages in their move out of home. These included the friendships that they made with other schoolmates and their flatmates. As they remained in the service beyond the age of 17 years, these friendships had become established. Harry explained that “meetings up are really good!” when talking about activities offered through his service provider. The services that supported them provided or facilitated access to more activities than they had at home. Andrew acknowledged that going to [disability service] had helped him to get more involved with other activities. George also noted that, through attending an onsite specialist school he was enjoying opportunities such as “going to the sensory room, doing art, talking to people, and typing things on the computer and many other things … I like music as well.”

More challenging to settling into a service were the multiple moves that the young people had within the service. A clear difference between Beatrice’s experience of care within another family and that of the majority who went into service delivered care was moving from one residence to another. Whilst Beatrice’s living situation remained constant, most of the others went through at least three “houses” while still under 17 years of age. For many there had been two or three subsequent moves as well. It was not clear from the data why these moves occurred. Andrew gave some indication that it could be in relation to funding for service provision “I stayed there [first home] the first 4-5 months … I was in respite care cos I was waiting for some payment to come through, some funds … until I was a full resident …”. However, there was also a pattern of regular moves for the young people who were at the on-site education service. David suggested that he had been “very naughty” when younger and that he thought that contributed to his moves. It should be noted that Elizabeth had been at school at the same time as David and had a similar number of moves for which she did not identify any particular reason.

An effect of the many changes of houses was the lack of continuity of support people. Although most were positive about the people that supported them, there did not appear to be long-term close attachments. As George noted, “people keep coming and going”, possibly referring to his years before as well as since entering the service he was now with. Andrew had a similar experience, listing off a number of names and regarding being able to talk to them “generally, … most of the time”. Harry had learnt that he could ask “any staff that are on …” when he wanted something. Elizabeth, Frances and David made similar comments, as David put it, the people at the service “were very helpful”.

Remaining part of the family

Whilst the young people had moved to another residence it was notable that they continued to have a strong attachment to their family and were all in contact with at least some members of their family at the time of the interview. Remembering the exact nature of the contact in the years before they were 17 was a struggle, however it was possible to pull some key points out and consider these in light of how they had described their current relationship.

It was common for all those who were geographically separated from family to go home for school holidays, with the general comments from most summed up by Elizabeth “In the school holidays we did [go home]”. She remembers “I used to fly on the aeroplane with [other student], from [place] to [place], and then [house parent] used to put us on the plane to meet our parents and tell them how our term was”.

Living in closer proximity to family meant more regular face-to-face contact could occur. For example, after initially being restricted in visiting his mother, Andrew gradually built up to going home for weekends noting that at first, “… it was just afternoons with Mum. It took a couple of years to start sleepovers again …”. At that point he was also seeing his father and his new family “every second weekend”. Harry’s parents lived in another town but travelled every three weeks to spend the weekend with their sons in addition to them going home for holidays.

Aside from physical visits, letters, cards, phone calls and more recently emails and facebook have all been part of the way in which the young people remain engaged with their family. Whilst interviewing him, Charles demonstrated his statement “I always talk to my Mum and Dad, always”, by phoning his father there and then so that the researcher could “meet” him. George had telephone contact with his grandparents “Once a week …”. Elizabeth remembered that her mother would “… phone me every now and again”. Just as Andrew noted, the impression Elizabeth and Frances gave was of relationships with their respective mothers that might have been strained when they first went into care but had built up again over time.

In summary, while the reasons for each person being placed out-of-home might have been different, there were some similarities in their perceptions of how that had felt to them, the support that they had and their ability to maintain contact with their family. As a Section 141 agreement expires when the young person turns 17 years of age there might be the expectation that some planning would go into the time when the agreement ends. The next theme explores what the young people knew about this transition period.

Transitioning from Section 141

Although it might be expected that there would be planning for the young person transitioning from a placement made under a Section 141 agreement, the findings of this research suggest that any transition planning that did occur was more closely aligned to leaving school. For the majority of the young people interviewed, the ability to remain within the education system until the age of 21 years had been applied. Indeed, Beatrice and Andrew were the only ones that had left school at 18 years, although George also indicated that he would like to leave when he turned 18. Charles was leaving school at the end of the year and Harry had one final year. Of those still at school, Charles attended the local secondary school, whilst Harry and George attended the school attached to their service provider. In reporting the following results there has been no attempt to separate transition through education from the expiry of a Section 141 agreement.

Amongst the larger group of people living in a service that also provided their education, there was evidence that some understood and felt they had choices as they were leaving school. For example, Elizabeth said about the transition class that she understood its purpose and in terms of participation …"Yes I did. They asked me where I wanted to have my work experience and I told them in C". Frances had similarly understood some of the process and felt she had chosen what she wanted to do. In contrast David, who would have left school about the same time as Elizabeth, could not remember there being a plan in place. Harry was in the process of planning his transition from school and when asked noted that his key worker had talked to him about what he would like to do. His key worker was supporting him at the interview and added that they had talked about Harry's goal of moving into independent flatting in the future. Harry added that his studies at school were also preparing him as he was learning about "how to buy things and stuff …". From his special class at the local high school, Charles had two jobs based within the local community that were seen as work experience. In addition he was learning on the computers at the local library. He enjoyed these activities and appeared to have some understanding that they were related to his transitioning from school.

Whether or not plans were in place, it was clear that some of the young people were thinking about their future. George was keen to gain independence “I would like to learn how to drive a car next year …” and while he had not yet had work experience his aim was “… to be a hairdresser and after that I would like to be a teacher …”. Whilst George was very articulate, his support person suggested to the researcher that some of his ideas grew when he had a forum to express them. During the interview he had been asked what support he thought he would get from staff regarding his goal to learn to drive and his response had been “they would say no wait until you’re in [another town], or they might say be really independent and we can show you.”

As noted above, Andrew left school at 18 years. He had been in mainstream classes throughout schooling, with additional support coming from peer mentoring, a teacher aide and resource teachers. Although he knew that the Section 141 ended when he turned 17 years, the meaning of that was not clear to him and he felt “stuck in a residential home”. As far as he was aware there was no plan in place. Even five years out he is still unsure as to the role of his service in making decisions for him “I guess I’m sort of unsure whether they have authority or approval type of thing”, was his response in terms of who controls his money.

In summary, the young people appeared to have little information about their status after the Section 141 out-of-home placement agreement ended. There was no evidence of their understanding about terms such as guardianship and having autonomy. We did not enquire about other legal arrangements that might be in place and relevant to their current status within the service that supports them.

Discussion

Section 141: A pathway to a life in services?

An important finding from the research was that none of the young people who had entered a service under Section 141 had subsequently left. While one person moved services within the first year, the reason for the move was not explained and he was still under 17 years of age at the time. Few of the young people demonstrated much understanding of why they were initially placed out-of-home, although, as noted in the results, some did have some insight when they thought back on what was happening at the time. Interestingly, the Act does make provision for annual review of placements but there was no evidence that the young people themselves had been involved in such reviews regardless of their age or ability to provide input. Reviews that were inclusive of the young people would provide an opportunity for them, as they matured, to gain a greater understanding of the context to their placement. It would also provide the young person with a voice and, perhaps, some advocacy when they turned 17 years and wanted to explore other options of care. Under the current Act there is no independent social worker involvement with young people under Section 141, and whilst services are expected to have current annual plans for each individual, there is a potential conflict of interest if that person wants to seek placement with a different service. Amongst the suggestions from the Office of the Children's Commissioner (2015) was a need to ensure all children under statutory care arrangements were getting the best possible support. Best possible support should include the opportunity to make choices about service provision as a person matures and gains greater understanding, even if for some they continue to be reliant on formal disability support.

Whilst Section 141 legitimises a shift in duty to care from the parent to the nominated service or care provider, the lack of a pathway to transition to either independence or an alternative adult provider when they turned 17 years of age meant that the young people were limited in their ability to express any relevant experience. As noted in the report from the Office of the Children's Commissioner (2015), neglect of young people exiting services at age 17 years is a concern for those for whom CYF have responsibility. Although the young people in the current study might be less eloquent in expressing their thoughts and they remain embedded within the service that is supporting them at the time, the evidence suggests that no more thought has gone into what happens to them than goes into the future of their age peers who are in CYF's care. Such transition planning that did occur was focused on their education which, for most of them, meant leaving school at age 21 years. Leaving school at 18 years, as we saw with Andrew, meant no transition planning of any substance, unless the young person had a strong advocate, as was the case with Beatrice. It has to be considered whether the lack of social work involvement is an issue here. An identified social worker might provide some continuity and less potentially biased oversight about what a young person’s future could hold.

Keeping connected to family

Despite the fact that Section 141 or 142 placements are for the most part instigated by their parents, participants in the current study did not appear to hold anger or bitterness toward them for the decisions that led them to be placed in care away from their family home, or as one young participant described it “excluded from the family table”. A significant theme evident within the data related to the importance and pleasure that the young people associated with keeping connected to their parents and extended family. Almost without exception participants talked of the ways in which they kept in touch with their parents and other family members. Most young people spent some time at the family home, were visited by their parents, received letters and cards from time to time, and used the telephone and other forms of social media to stay in touch. Consistent with other research that has explored the social relationships of young people, the current study highlighted that for most of the young people family relationships, even when troubled or broken, still remained the most constant in their lives (Stevens et al, 2014). The recent Children’s Commissioner’s Report (2015) highlighted that young people had asked to be supported to maintain positive relationships with their birth family and whānau. The young people in this research did not explicitly request this support, but their focus on family was clear through their conversations with the research team. When considering the ongoing needs of young people in out-of-home placement, a commitment to ensuring that family and whānau relationships are able to be repaired and actively maintained is critical. In a 2012 study (Foley, 2012) young people with learning disability identified family, friends and feeling good about themselves as the elements that enabled them to develop a sense of wellbeing. It would not seem too much of a stretch to assume that it is even more critical to pay attention to these areas of life when disabled young people are living away from home.

Making meaning and building memories within services

While the young people who participated in this study continued to have a focus on staying connected to family, that did not stop them developing a new sense of “home” of sorts within disability support services. Almost all of the young people, by the time that they were interviewed, had spent significant periods of their lives living within residential disability services. In this environment it was common for them to have undertaken multiple moves within their particular service and, in one case, between services. It is notable that the participants did not see anything particularly negative about this experience of "home" being temporary and not necessarily linked to a single house, but rather to a disability service environment. This might suggest that the young people in this study who relied on residential services had become accustomed to service life to such an extent that frequent shifts and changes were expected, and that they did not see themselves as having any control over where and with whom they lived. Article 19 of the UNCRPD, which asserts a person's right to live in a place of their choice with people of their choosing could be seen as being breached through the common practice of relocating individuals to respond to the needs of the service.

While it is difficult to interpret due to the low number of disability services represented, there was a perceptible difference between services in the extent to which the needs of the whole young person were recognised and responded to. Some services (and the foster mother) appeared to be more cognisant of the developmental needs of young people and consequently tried to engage them in a process of planning for the future. Other services seemed to be more focused on managing the young person and his or her needs on a day-to-day basis, without strong consideration of what their future might look like or offer them. This difference in orientation was not dependent on a young person's ability.

Despite the constraints apparent in residential settings, all of the young people had positive things to say about their service, felt their material needs were met, and engaged in a range of activities they enjoyed. Many reported close friendships with their peers in the disability support service, some of which had originated in educational settings. Support staff were generally seen as helpful, however we did not see the evidence of the importance of strong relationships with individual support staff that young disabled people have reported in other research (Abbott, 2001). Again, it may be the case that the frequent shifts in accommodation are mirrored by frequent changes in support staff thus close relationships may not have the opportunity to develop. It is important to note that Beatrice, as the one participant who lived in a family situation, had a close relationship with her foster mother and siblings, and an extremely close bond with her support "friends."

Limitations of the research

This research was conducted under a tight timeframe to ensure the inclusion of the views of young people directly impacted by Section 141 out-of-home care in the Disabled Children Project. This timeframe meant decisions were necessary regarding the degree to which young people could be included in planning the research, the method utilised for data collection and analysis, and the acceptable number of participants.

As noted previously, inclusion of young people with learning disabilities in planning the research can lead to a wider range and more appropriate strategies with which to access the ideas of their peers who choose to participate in the study. In addition, including the option to visit individuals multiple times, to spend time interviewing, interacting in less formal ways and observing can provide richer data. For virtually all of the participants interviewed, the researchers were of the opinion that additional less formal time spent with them would have resulted in a greater understanding of the young person's experience of living away from home under a Section 141 agreement. Multiple visits might have been particularly useful for the people who had ASD. As also noted by Preece and Jordon (2010) in their interviews with young people with ASD, concentration on the interview questions was a struggle for some and interviews were cut short when the person had clearly reached their limit. One potential participant was identified as too uncomfortable to persist beyond introduction. Whilst the team sought advice on the information sheets and consent forms, there was not time to engage more comprehensively with young people with learning disability as advisors, nor to spend time with individual participants. Thus the data from many of the individuals is a "snapshot" of their thoughts at the time.

The Ministry of Health led participant recruitment. Although they sent out invitations soon after ethics approval, responses from services were slow. There was an initial response from some families who received the invitation and information sheet but whose child did not meet the inclusion criteria either due to age (under 17 years) or because they had not committed to a section 141 even though it might have been considered. Ultimately, eight participants were identified, which is a comparatively small number from which to draw conclusions. In addition, three services and one foster family provided care to the eight participants, with one service disproportionally represented.

Conclusion

This small exploratory study has provided an insight into the experiences and views of disabled young people who have been been placed in out-of-home care under a Section 141 of the Children, Young Persons, and Their Families Act agreement. While the individuals who chose to take part in this research reported reasonably positive experiences, there was evidence that their life choices were constrained. Article 23 of the UNCRPD emphasises the right for disabled children to not be segregated, however, it might be implied that placement within a service that includes a special school are being segregated as a function of their Section 141 placement. Article 7 notes that disabled children should have the right to express their views on all matters affecting them. Despite being able to participate in research interviews as part of this work, only two of the young people reported that they had attempted to contribute to Section 141 decisions. Neither of these contributions led to a significant revision of the planned process. Article 23 recognises the importance of children remaining within their family where at all possible. Given that all young people reported strong relationships with their families it might be assumed that the young people and their families had an enduring commitment to each other. What is not clear from this research is whether alternative solutions to the issues leading up to a Section 141 were sufficiently identified and implemented. When out-of-home placement occurs, proximity would seem to be important to maintaining family relationships. However, in this study many of the young people moved a geographical distance from their family. Finally, the pivotal role of disability support services in the lives of these young people was evident. The concern that this reliance on a single service raises is the lack of independent advocates, such as a social worker, who could help young people navigate life beyond the age of 17 years. As eloquently expressed by Andrew there is a real danger of young people who become subject to Section 141 or 142 agreement in childhood becoming caught within a cycle of service dependence. His words are a fitting conclusion to this report: “I thought if I walk through those doors will I come back out those doors again?”

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Appendices

1. Letter of invitation
2. Information Sheet (regular)
3. Participant Interest Form
4. Information Sheet (easy read)
5. Consent Form (easy read)
6. Responding to abuse protocol
7. Interview Schedule

Appendix 1: Letter of invitation

Ministry of Health Letterhead
Date

WE WOULD LIKE TO INVITE YOU TO TAKE PART IN THE LIVING AWAY FROM HOME STUDY

Dear [NAME]

The Ministry of Health and the Ministry of Social Development are working together on the Disabled Children's Project. The Disabled Children's Project is looking at how things could be better for disabled children who have to live away from home.

As part of this project, researchers from the Donald Beasley Institute have been asked to talk to young adults who were in care when they were young. The Donald Beasley Institute has done a lot of research with disabled people.

Because you lived in care when you were younger, we would like to invite you to take part in the *Living away from home study.*

The Ministry of Health has your contact details on record. They will only let the research team know what they are if you would like to take part in the study.

Please have a look at the information about the study. Get someone to explain things to you if you need their support. If you would like to take part please fill out the pink form.

It is okay if you don't want to take part in the study. The researchers will not be told your address or phone number if you do not want to take part.

Thank you for thinking about taking part.

[NAME OF MINISTRY CONTACT]

Appendix 2: Information Sheet (regular)

DONALD BEASLEY
INSTITUTE

Participant Information Sheet

Study title: **Living Away From Home**

This study is being done by: **The Donald Beasley Institute**

You are invited to take part in a study about what it was like for you to live away from home when you were younger.

This Participant Information Sheet will help you decide if you'd like to take part.

Taking part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the support you receive.

If you do want to take part now, but change your mind later, you can pull out of the study at any time.

Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or the people who support you.

If you would like to take part in this study, fill out the pink Participant Interest Form.

Please put the completed interest form in the envelope provided and post it.

OR

Telephone either Brigit Mirfin-Veitch or Jenny Conder on Phone:

03 479 5861 or 03 479 8689

and they will write your answers on an interest form.

OR

Email Brigit Mirfin-Veitch (bmirfin-veitch@donaldbeasley.org.nz) with your answers.

If you agree to take part in this study you will be asked to sign a Consent Form when we visit you. We will talk to you about the study before you sign the consent form.

You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 9 pages long, including the Participant Information Form and the Consent Form. Please make sure you have read and understood all the pages.

What is the purpose of the study?

The Disabled Children's Project is carrying out a review of how disabled children come into care, and their experiences when they are in care. The Disabled Children's Project is made up of people who are interested in disabled children and children's rights. They have asked the Donald Beasley Institute to do the study with young disabled adults who were in care when they were young. The Ministry of Social Development is paying for the study to be done. Both the Ministry of Social Development and the Ministry of Health will get a copy of the report.

Brigit and Jenny from the Donald Beasley Institute would like to interview young adults aged between 18 and 22 years about what it is like to be in care as a child. The information that comes from the study will be used by the Disabled Children's Project to change the way disabled children who come into care are supported. We hope that by learning from people who have been in care when they were young, we will be able to make things better for disabled children in care now and in the future.

What will taking part in the study mean for me?

You have been asked to take part in the study because you were in care as a child.

If you choose to take part in the study, a person from the Donald Beasley Institute will visit you and talk to you about what being in care was like for you.

The person that will visit will be either:

Brigit

Jenny

We will visit you once.

The visit will be for about one and a half hours.

We will visit you at home or at another place where we can talk in private and where you feel comfortable.

We will bring equipment to record our talk.

We will ask you questions about when you were young and what it was like to be in care.

You can bring photos or other things to show us what is important to you.

Brigit or Jenny will give you a $30 Warehouse voucher as a thank you for taking part in the study.

What are the possible risks of this study?

Talking about being in care might be hard for you and we know that you could get upset.

You can ask us to stop the interview.

We will make sure that you get support if you want it.

What are my rights?

It is your choice whether or not you take part in the study.

You can have a support person with you when we talk to you.
You can stop taking part at any time and you will not be affected in any way.

What you talk about will be between you and the people from the Donald Beasley Institute. No information that could identify you will be used in reports of this study.

You can ask to see the information that we have written about you after our talk.

What happens after the study?

We will send you a copy of the report, easy read report or both. The report will be written after we have talked to everyone that wants to take part.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Brigit Mirfin-Veitch

Telephone number: 03 479 5861
Email: bmirfin-veitch@donaldbeasley.org.nz

Name: Jenny Conder
Telephone number: 03 479 8689
Email: jconder@donaldbeasley.org.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS (0800 4 384 427)
Email: hdecs@moh.govt.nz

Appendix 3: Participant Interest Form

DONALD BEASLEY INSTITUTE

Living Away From Home

Participant Interest Form

If you would like to take part in the study about being in care please answer these questions. You can ask a friend, family member or support person to help you.

1. Name:

2. Address:

3. Phone number:

4. In what town do you live?
5. Gender: Male Female

6. Ethnicity:
   Pakeha/ NZ European
   Māori Iwi ____________________
   Pacific Island
   Asian
   Other ____________________________

7. How old are you?

8. When did you leave care?

9. Are you supported by a disability service?

   yes no

10. What is the name of the disability service?

11. Would you like a support person to be with you when we talk to you?

   yes no

If yes, write their name and telephone number

Name of support person:

Telephone number of support person:

Please put the completed interest form in the envelope provided and post it.

OR

Telephone either Brigit Mirfin-Veitch on 03 479 5861 or Jenny Conder on 03 479 8689 and they will write your answers on an interest form.

OR

Email Brigit Mirfin-Veitch (bmirfin-veitch@donaldbeasley.org.nz) with your answers.

Appendix 4: Information Sheet (easy read)

DONALD BEASLEY
INSTITUTE

Information sheet for people taking part

'Living away from home' study

Easy Read 2015

What is this study about?

You are invited to take part in a study about what it was like for you to live away from home when you were younger.

This **information sheet** will help you decide if you'd like to take part.

Taking part is **your choice**.

If you **do not** want to take part you **do not** have to give a reason why.

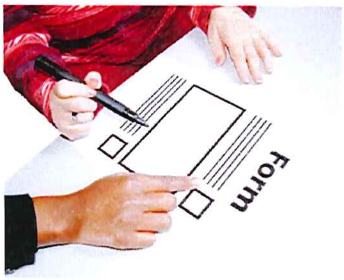
If you choose not to take part it will **not** change the support you get.

If you choose to take part **now** and **change your mind later** you can pull out of the study at any time.

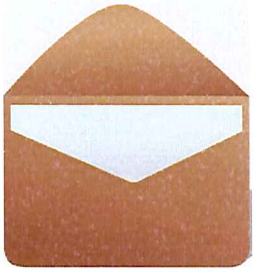
Before you choose you may want to talk about the study with other people like:

- family/ whānau
- friends
- people who support you.

How to take part



If you would like to take part in this study fill out the pink **interest form**.



When you have filled it in please:

- put the pink **interest form** in the envelope we give you and post it

or

- call **Brigit Mirfin-Veitch** or **Jenny Conder** and they will write your answers on the form

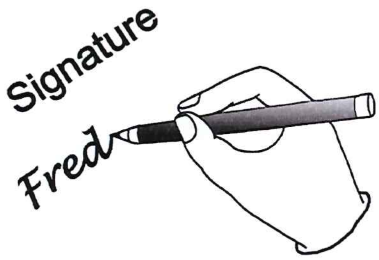
Phone: 03 479 5861 (Brigit)
03 479 8689 (Jenny)

or

- Email **Brigit Mirfin-Veitch** with your answers:

bmirfin-veitch@donaldbeasley.org.nz

What happens if you agree to take part?



If you agree to take part in this study you will be asked to sign a **consent form** when we visit you.

Consent means you agree to:

- taking part in the study
- the study using your words and ideas.

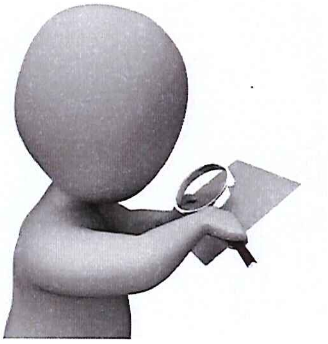
We will talk to you about the study before you sign the consent form.

You will be given a copy of both the **information sheet** and the **consent form** to keep.

This document is ***20*** pages long.

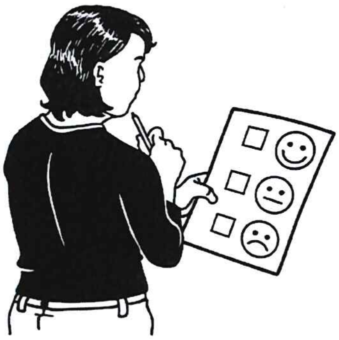
Please make sure you have read and understood all the pages.

Why are we doing this study?



The **Disabled Children's Project** is looking into:

- why disabled children sometimes live away from home
- the experiences of disabled children when they live away from home.



The **Disabled Children's Project** is made up of people who are interested in disabled children and children's rights.

They have asked the **Donald Beasley Institute** to do the study with young disabled adults who lived away from home when they were young.

MINISTRY OF SOCIAL DEVELOPMENT
Te Manatū Whakahiato Ora

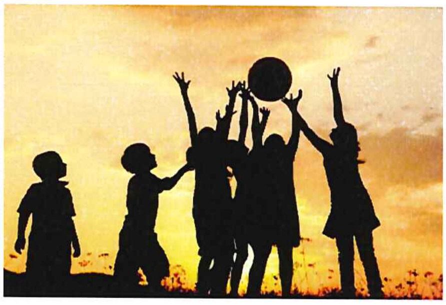
The **Ministry of Social Development** is paying for the study to be done.

A copy of the report will be given to these government departments:

- **Ministry of Social Development**
- **Ministry of Health**.

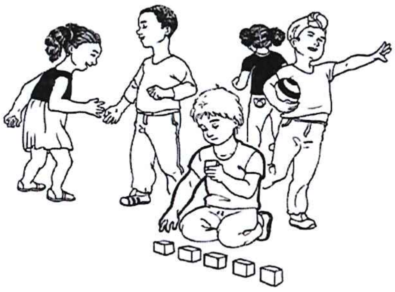
Brigit and Jenny from the **Donald Beasley Institute** would like to talk to young adults aged between **17 and 22 years** about what it is like to live away from home as a child.

The **Disabled Children's Project** will use what people say to change the way disabled children who live away from home are supported.



By learning from disabled people who have lived away from home when they were young things can be made better for disabled children living away from home now and in the future.

What will taking part in the study mean for me?



You have been asked to take part in the study because you lived away from home as a child.

If you choose to take part in the study a person from the **Donald Beasley Institute** will visit you and talk to you about what living away from home was like for you.

There are 2 people that might visit you.

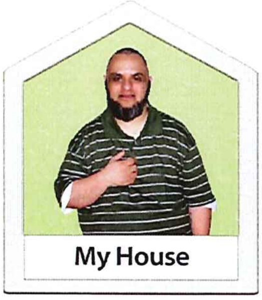
Their names are:

- **Brigit**

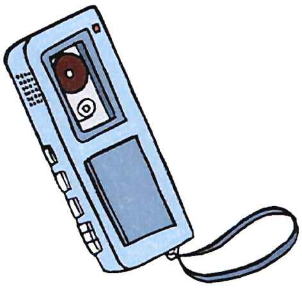
- **Jenny**

1 of these people will visit you **1 time**.

The visit will be for about **1 and a half hours**.



They will visit you at home **or** at another place where you can talk in private and where you feel comfortable.



They will bring some things with them to record the talk.

They will ask you questions about when you were young and what it was like to live away from home.

You can bring photos or other things to show them what is important to you.

Brigit or Jenny will give you a **$30 Warehouse voucher** as a thank you for taking part in the study.

What could happen?

Talking about living away from home might be hard for you and we know that you could get upset.

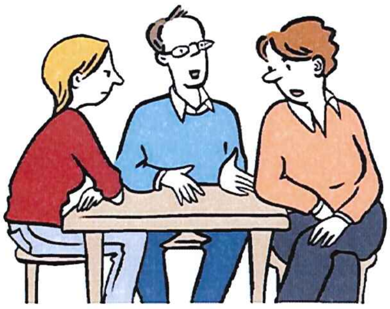
If you tell us you have been abused, we will ask if you want help. If we think you or anyone else is in danger, we will talk to other people who can help.

We will make sure that you get support if you want it.

You can ask us to stop the interview.

What are my rights?

It is your choice whether or not you take part in the study.



You can have a support person with you when we talk to you.

You can stop taking part at any time.

If you choose to stop taking part that is okay.

Nothing bad will happen.

What you talk about will be just between you and the people from the **Donald Beasley Institute**.

The report will not say anything that might make it easy for people to know it is:

- about you
- what you said.

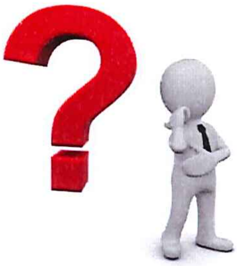
You can ask to see the information that we have written about you after our talk.

What happens after the study?

We will send you a copy of the report, Easy Read report or both.

The report will be written after we have talked to everyone that wants to take part.

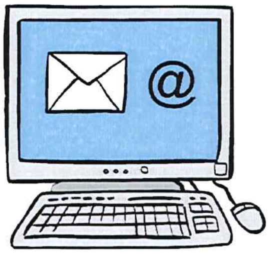
Who to contact for more information or if you are worried



If you have any **questions**, **worries** or **complaints** about the study you can contact:

Brigit Mirfin-Veitch

Phone: **03 479 5861**



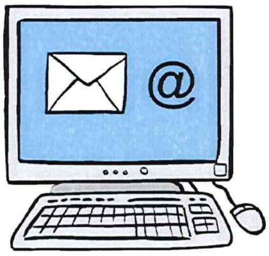
Email:

bmirfin-veitch@donaldbeasley.org.nz

You can also contact:

Jenny Conder

Phone: **03 479 8689**



Email:

jconder@donaldbeasley.org.nz

Health & Disability Advocacy
Ngā Kaitautoko

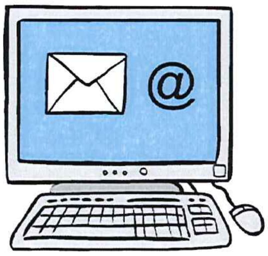
If you want to talk to someone who is **not** involved with the study, you can contact an independent **Health and Disability Advocate** on:

Phone:

0800 555 050

Fax:

0800 2787 7678



Email :

advocacy@hdc.org.nz

You can also contact the **Health and Disability Ethics Committee** (**HDEC**) that approved this study on:

Phone:

0800 438 4427

Email:

hdecs@moh.govt.nz

This has been translated into Easy Read in consultation with People First New Zealand Inc. Ngā Tāngata Tuatahi.

Appendix 5: Consent Form (easy read)

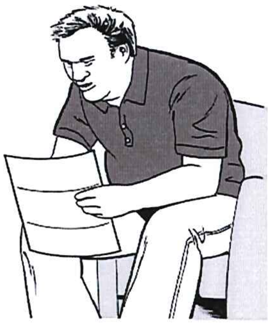
DONALD BEASLEY INSTITUTE

Consent Form

'Living away from home' study

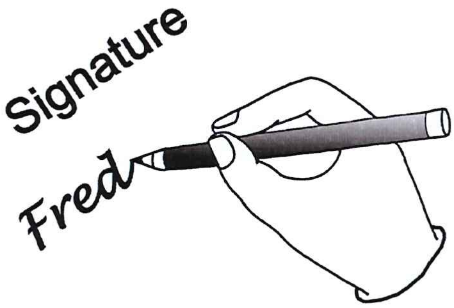
Easy Read 2015

Taking part in this study



If you want to take part in this study please read this form or have someone read it to you.

It tells you what **your rights** are when you take part in the study.

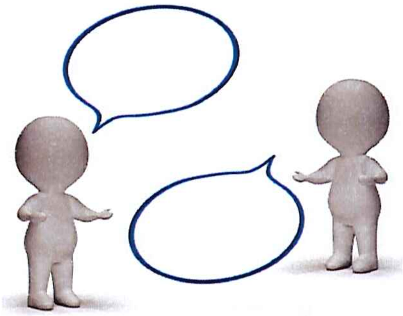


If you sign this form you are saying that you want to take part in the study.

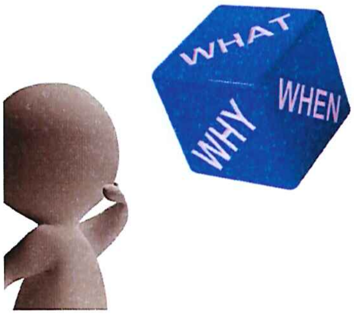
Please read carefully

1. I have read (or had read to me) the information about the study.

2. I understand the information that I have been given.



3. I have had a chance to talk to a person from the **Donald Beasley Institute** about the study.



4. I have been able to ask questions.

I have had all my questions answered.

5. I have been able to have a friend, family or whānau member, or support person with me when I learned about the study.

6. I understand that taking part is **my choice**.

7. I understand that I don't have to take part.

8. I understand that I can **stop** taking part at any time.

It is okay if I choose to stop taking part.

Nothing bad will happen.

9. I understand that my taking part is **private**.

When reports are written my **name** and **other details** will be changed.

This is done so that your identity is safe and no one will know it is you.

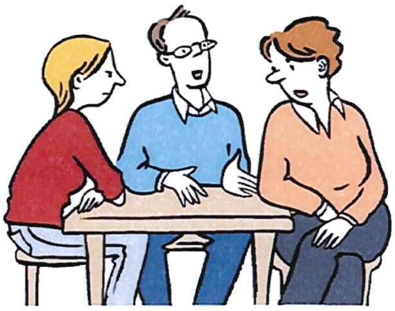
10. I understand that my personal information will be kept **private**.

11. I know what will happen if I talk about abuse in my interview.

The people from the Donald Beasley Institute will **not** talk to any other person about me unless:

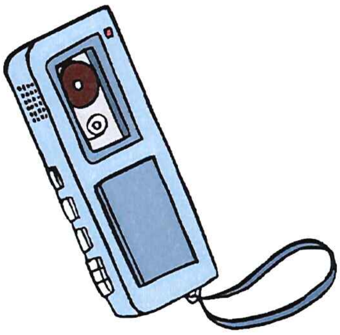
- I am in **danger**
- someone else is in **danger**.

12. I have had enough time to decide if I want to take part in the study.



13. I understand that I can choose to have a support person with me in the interview.

14. I understand that I will be interviewed.



15. I understand that the interviews will be **recorded**.

16. I know that I can ask to have the recorder **turned off** at any time during an interview.

17. I know that the person talking to me may also write notes about our talk.

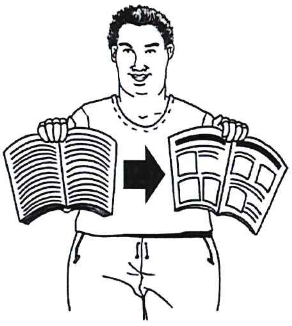
18. I know that I will have the chance to:

- go through the written information about me
- make changes if I want to.

19. I agree that Donald Beasley can use the words I say.

Yes ☐ **No** ☐

20. I know my name in will **not** be used in the report.



21. I know that I will get a final report, Easy Read report or both.

Health & Disability Advocacy
Ngā Kaitautoko

22. I know that I can contact a **Health and Disability Advocate** if I want to know more about my rights.

23. I know that I can contact **Brigit Mirfin-Veitch** or **Jenny Conder** if I have any questions.

Declaration by person taking part:

I agree to take part in this study.

Name of person taking part:

Signature: **Date:**

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: **Date:**

This has been translated into Easy Read in consultation with People First New Zealand Inc. Ngā Tāngata Tuatahi

DONALD BEASLEY INSTITUTE

Consent Form

Study title:	**Living Away From Home**
This study is being done by:	**The Donald Beasley Institute**

If you want to take part in this study please read this form or have someone read it to you.

It tells you what **your rights** are when you take part in the study.

If you sign the form you are saying that you want to take part in the study.

1. I have read (or had read to me) the information about the study.
2. I understand the information that I have been given.
3. I have had a chance to talk to a person from the Donald Beasley Institute about the study.
4. I have been able to ask questions and I have had all my questions answered.
5. I have been able to have a friend, family or whānau member, or support person with me when I have learned about the study.
6. I understand that taking part is my choice.
7. I understand that I don't have to take part.
8. I understand that I can stop taking part at any time and I won't be affected in any way.

9. I understand that my taking part is private. When reports are written my name and other details that might identify me will be changed so that no one else will know it is me.
10. I understand that my personal information is confidential. The people from the Donald Beasley Institute will not talk to any other person about me unless I am in danger or someone else is in danger.
11. I know what will happen if I talk about abuse in my interview.
12. I have had enough time to decide if I want to take part in the study.
13. I understand that I can choose to have a support person with me in the interview.
14. I understand that I will be interviewed.
15. I understand that the interviews will be recorded.
16. I know that I can ask to have the recorder turned off at any time during an interview.
17. I know that the person talking to me might also write notes about our talk.
18. I know that I will have the chance to go through the written information about me and to make changes if I want to.
19. I agree to be directly quoted, but not identified, in the research report.

    Yes No (please circle one)
20. I know that I will get a final report, easy to read report or both.
21. I know that I can contact a health and disability advocate if I want to know more about my rights.
22. I know that I can contact Brigit Mirfin-Veitch or Jenny Conder if I have any questions.

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

Appendix 6: Responding to abuse protocol

DBI DONALD BEASLEY
INSTITUTE

Living Away From Home:

The Experiences of Young Adults

What happens if you tell me you have been abused?

The researchers have worked with disabled people for a long time.

They know that sometimes disabled people have been abused.

The researchers have a plan about what will happen if you tell them you have been abused.

The researchers will ask you what you want to happen before they do anything.

If the abuse has happened in the past, the researchers will check to see whether you got help. If you didn't, or you feel it wasn't enough help, the researchers will tell you where you could go for counselling or other support.

If the abuse is happening now, the researcher will talk with you about whether you want help. If you want help, the researchers will support you to find that help. You can talk about your own abuse but you do not have to do anything about it.

Sometimes the researchers may have to put a plan in place whether or not you want them to. This is when you tell them about abuse that is still happening and they think other children or adults might not be safe. The researcher will tell you before they talk to other people who can help.

Appdendix 7: Interview Guide

Living Away From Home: The Experiences of Young Adults

Interview Guide: Young Disabled Adults

Participant ID: **Interview Date:**

The interview will commence with general “getting to know” each other conversation. This helps the participant to become more comfortable with the researcher before more personal topics are approached.

The interview guide is indicative of the subject matter to be covered. While this guide includes the intended topic areas, it must be noted that the researchers will be responsive to additional or unanticipated topics that participants may raise.

1. What is your current situation?
    a. Where do you live?
    b. Who do you live with?
    c. What do you usually do during the week? Do you work? Where?
    d. What are your interests?
2. What age where you when you went into out of home care?
3. Do you remember the support you and your family were given before you left the family home?

4. Did you live with another family before living in residential/support service care?
    a. If so, why did you move?
5. Where did you go for out of home care?
    a. How many places were you in?
6. What did you like about the places you lived in?
    a. Activities
    b. Facilities and care (staff, food, room etc)
    c. Relationships
7. What could have made it better?
8. How many people were there?
9. How did you get on with the people you lived with?
10. Who supported you?
11. Did you get to have things with you that were important to you?
12. Did you see your family?
    a. Did they come and visit you?
    b. Did you visit home? If so, how did these visits go?
    c. Did they phone, email, or Skype you?
    d. How often did this happen?
    e. Were they good conversations/meetings?
13. Is there anything you didn't like about living in out of home care?
14. Were you involved in the decision to leave home or where you went?
15. Did you ever wish you lived somewhere else?
    a. If so, where was that and with whom? E.g. another family member, non-kin carer
16. What happened when you turned 17?
17. Did you get to contribute to a transition plan for when you left care?
18. Did you have someone in the residential home that you could talk to if you were not happy? E.g. staff, outside person, family
19. Who were your friends there? e.g. other children, staff, visitors
20. What trips outside did you go on? E.g. community activities
21. Is there anything else you would like to tell me about?