Submission to the Community Affairs References Committee Inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

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About CREATE Foundation

CREATE Foundation is a peak consumer body representing the voices of all children and young people in out-of-home care.

CREATE Foundation is national and has offices in all of Australia's states and territories. As the national consumer body advocating for children and young people with a care experience, CREATE seeks to provide opportunities for children and young people to have a voice and be heard. CREATE is unique in that it is one of only a handful of organisations in the world, and the only organisation of its kind in Australia expressly established to advocate on behalf of children and young people in care.

CREATE's mission is to create a better life for children and young people in care, including those who are or have been the subject of care and protection orders. CREATE achieves its mission by **connecting** children and young people with a care experience to each other and their community, **empowering** them to develop in order that they may realise their potential, and **changing** the care system, in consultation with children and young people through advocacy to improve policies, practices and services.

CREATE engages with children and young people at fun events, holding regular Youth Advisory Group meetings to discuss ideas and issues generated by children and young people, conducting formal consultations with children and young people to have input to resources, programs and policies, training young people to be advocates for themselves and others within child protection systems, and financial help and skills development to help young people transition to independence.

Young Consultants participate in child protection conferences and meetings to provide their direct experiences of child protection systems to child protection workers, senior staff and politicians. It is CREATE's view that improvements to the system must be informed by the knowledge and experiences of the children and young people who live or have lived in out-of-home care.

With major inquiries and reviews into child protection being conducted, and at various stages of consultation and implementation, in all states and territories in recent years, as well as the national Royal Commission into Institutional Responses to Child Sexual Abuse, CREATE continues to consult with children and young people to obtain their views.

CREATE has a national research program, informed by the views of children and young people in out-of-home care, that drives its advocacy work. CREATE's Report Cards are national research projects conducted every one to two years focussing on issues facing children and young people in care. Some of the single issues CREATE has looked at include, education, health and transitioning to independence. The most recent Report Card surveyed children and young people in out-of-home care as a benchmark measure towards the National Standards for Out-of-Home Care. CREATE's research provides an opportunity for children and young people to give their views on how they are faring and how the state and territory child protection systems are working. These views also inform other research projects, most recently a report into sibling and family contact in the child protection system. Importantly, CREATE's research allows for the views of children and young people to be expressed independently, without influence of political or bureaucratic priorities.

Introduction

CREATE Foundation thanks the Senate Community Affairs References Committee (the Committee) for the opportunity to respond to the Terms of Reference (TOR) of its inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia (Senate Inquiry).

CREATE believes the voices of children and young people in out-of-home care, relaying their own experiences and views, is crucial to any discussion about the child protection system. With this submission, CREATE will comment on the experiences and outcomes for children and young people with a disability who are, or have been in statutory out-of-home care systems. This relates mostly to TOR c. *the health and support pathways available to young people with complex needs*.

CREATE urges the Senate Inquiry to communicate directly with young people who have a disability and their advocates about their views on the adequacy of existing residential care arrangements.

In 2010, 6,456 people under the age of 65 years were residing in aged care facilities, with 28 of those young people being under 29 years old (Young People in Nursing Homes National Alliance, n.d.). The AIHW (2013) indicates the number of people under the age of 50 years in aged care and entering aged care has decreased between 2008 and 2012. CREATE is not specifically aware of young people exiting out-of-home care into aged care facilities but it would appear highly likely given the problems in the pathways, generally, for young people leaving care into suitable accommodation.

In 2012, CREATE Foundation published a Literature Review, "Supporting children and young people with a disability living in out-of-home care in Australia"[1]. The main findings within the literature included:

- It is unclear whether Australian child protection authorities are providing the necessary care and assistance to meet the needs of children and young people with a disability.
- A social model approach to disability support, where the emphasis is on assisting people with disabilities to overcome social and economic barriers to maximise their participation in their communities, is more useful for meeting the needs of children and young people than viewing disability as a "medical condition or illness".
- There is no uniform definition of "disability" across the eight state and territory child protection jurisdictions in Australia, making it difficult to accurately and consistently measure how many children and young people in out-of-home care have a disability. Without this knowledge it is impossible to say whether the support needs of children and young people with a disability are being identified or met. It is also important for supporting carers and training staff.
- While the number of children and young people with a disability in out-of-home care in Australia is unknown, it is generally accepted that children and young people with a disability are over-represented in out-of-home care in Australia. The literature indicates it varies from as few as 4% of all children and young people in care to as many as 60-70%.
- The lack of data and consistency in understanding issues for children and young people with a disability in out-of-home care makes it difficult to identify trends in outcomes for these children and young people.

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[1] A copy of the literature review can be accessed at http://create.org.au/wp-content/uploads/2014/12/03.-CREATE-Research-Article_CYP-With-A-Disability-Living-in-OOHC_August-2012.pdf

- The number of Australian children and young people in care continues to grow and, increasingly, children and young people with high and complex needs are entering or are in the care system.
- There is evidence that children and young people with a disability are not well supported when they transition from out-of-home care, and many leave care without a planned and gradual "transition from care plan". The literature suggests that many young people with a disability leave statutory care without a carer, family support, education and employment prospects or somewhere suitable to live.
- There are a number of issues for children and young people with a disability who are in care that limit their chance of successful outcomes, including:
    - placement instability;
    - being placed in residential care rather than family based care (foster/kinship care);
    - low life and educational expectations;
    - the development of extreme and complex challenging behaviour;
    - high levels of mental health issues;
    - lack of educational and development opportunities; and
    - better supports needed at transitional points in education, placements and life stages.

Data

It is estimated that 7% of Australian children and young people under 25 years of age have a disability (AIHW, 2013). As noted above, there are wide variations in estimates of the number of children and young people with a disability in out-of-home care in Australia depending on how disability is defined and measured (CREATE Foundation, 2012). Children and young people with disability experience abuse and neglect at higher rates than their peers who do not have a disability but it is also likely to be underreported (Robinson, 2012). Children and young people who are or have been in out-of-home care are also recognised as one of the most disadvantaged groups in Australia, stemming from the reasons that brought them into care and their in-care experiences.

The CREATE Report Card 2013, interviewed 1,069 children and young people in care about their lives and experiences (McDowall, 2013). Of these children and young people, 241 (22.5%) identified as having a disability, with 68.9% of these receiving treatment or support (McDowall, 2013, p. 14).

DISABILITY	Number with a disability	Number receiving support
Intellectual (including Down syndrome)	23	16
Specific learning ADD	80	57
Autism (including Asperger's syndrome)	20	13
Physical	7	6
Neurological (including epilepsy)	6	5
Deaf/blind (dual sensory)	3	2
Vision (sensory)	12	5
Hearing (sensory)	9	5
Speech	9	7
Psychiatric (mental illness)	11	11
Developmental delay	5	1
Multiple disabilities	56	38
TOTAL	241	166

Table 1 Number of respondents who reported having the respective disabilities and who received support for that disability

Of those 166 children and young people who were receiving support in relation to their disability, the majority were living in foster care and kinship care, with 26 young people (15%) living in residential care. Of the 75 children and young people not receiving assistance related to their disability, it is not known if they do not require assistance or are perhaps missing out on much needed assistance.

In their issues paper, Children with Disability Australia highlight the need for research that canvasses the views of children and young people with disability on the impact of abuse and neglect in the lives of young people with disability (Robinson, 2012). This is needed as well as a better understanding of prevalence of abuse and neglect for children and young people with disability. To this end, the Australian Institute of Health and Welfare should be supported to collect and report on disability data through the Child Protection National Minimum Data Set (AIHW, 2014).

Residential care placements

At 30 June 2014, there were 43,009 children and young people in out-of-home care in Australia, with 2,356 (5.5%) in residential care (SCRGSP, 2015). Most children and young people in out-of-home care live in foster and kinship care placements, however, residential care is used where other suitable placements are unavailable. CREATE is of the view that other options to residential care need to be fully explored with input from the child or young person to achieve the best outcome for the child or young person.

All children and young people in out-of-home care (regardless of disability) have the right to be involved in their care planning to the full extent that they are able to.

While some young people report positively on their experience in residential care placements, the CREATE Report Card 2013 found that children and young people in residential care were less likely to report feeling happy in their current placement than those in kinship and foster care (McDowall, 2013). Children and young people in residential care experienced more disruptions in their placement history, which may in part explain this. Overall, the CREATE Report Card 2013 found the best predictor for children and young people feeling happy in their placement was how “at home” they felt.

There are two important considerations regarding residential care arrangements for young people with a disability in out-of-home care:

- **Family style placements are preferred because they support improved outcomes for children and young people; and**
- **Improving the amenity of residential facilities and staff training so that young people can feel “at home” in an institutional setting.**

An important part of young people feeling “at home” in their residential care placement, is having carers and staff who are able to provide support while respecting that first and foremost they are in someone’s home.

In general, a predictor of improved outcomes for children and young people in care is a safe and secure placement. The literature indicates that this does not happen for many children and young people with a disability in care, and the lack of support to transition between placements combined with frequent placement moves leads to poorer life outcomes. Young people with a disability in out-of-home care need supportive carers to champion their rights, particularly where a young person’s disability limits self-advocacy. In a residential setting where workers are looking after several young people or where staff turnover interferes with the necessary relationship building to ensure individual support for young people, then again life outcomes may be limited.

Another issue in residential care settings is where children and young people with a disability are housed together based on their having a disability rather than their individual needs or desires. The goal in child protection is to protect children and young people from harm, and as intervention can itself cause harm the placement should be designed for stability and safety, allowing children and young people to meet their potential in life. The driving decider should not be dictated by convenience and cost saving.

Transitioning to independence

In all states and territories, the government's legal responsibility for young people in out-of-home care generally ceases when they turn 18 years of age and legally become adults. At that point, young people's care providers, regardless of the model of care, are also no longer required (or funded) to provide ongoing support and unfortunately this means many don't.

The National Standards for out-of-home care, which are designed to improve outcomes for children and young people in out-of-home care, include the need for all young people to have a "transition from care plan" commencing at 15 years old, detailing the support to be provided after leaving care[2] (DFHCSIA, 2011).

Gradual, planned and supported transition to independence for young people in out-of-home care, with the full involvement of the young person, is needed to improve their post-care outcomes. Importantly it must address the needs of young people beyond 18 years, preferably until 25 years old.

Planning for young people with a severe disability, recognising any additional impact of having spent time in out-of-home care is critical to achieve positive life outcomes, and in particular safe, secure and appropriate housing.

Despite legislative and policy commitments of state and territory child protection agencies to transition planning, McDowall (2013) found that only 33% of eligible young people (n=93) who CREATE spoke to were aware of a "transition from care plan". Evidence shows that lack of planning for transition places young people at greater risk of homelessness, lack of educational attainment, underemployment, economic hardship, poverty, early and unwanted pregnancy, drug and alcohol abuse and engagement in the criminal justice system (CREATE Foundation, 2012).

For the general out-of-home care population, CREATE research found that for young people who had exited care:

- 60% did not have a leaving care plan;
- 35% were homeless in the first year of leaving care;
- only 35% completed year 12;
- 29% were unemployed; and
- 70% were dependent on some form of income support. (McDowall, 2009)

A recent report documenting the experiences of young people with a disability who had left out-of-home care found that most of them had never experienced living in stable long-term accommodation (Snow, Mendes, & O'Donohue, 2014). Nearly all of these young people (14 out of 15), identified as having multiple conditions and most of them were receiving the disability pension. Eight of the 15 young people were unaware of having had a formal leaving care planning meeting. The report highlights significant failings of the system while the young people were in care and lack of support

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[2] National Standard 13

post care, leading to young people having poor housing, education and employment outcomes (and prospects) (Snow, Mendes, & O'Donohue, 2014).

In one case study, Snow, Mendes & O'Donohue (2014) talk to Luke about his journey through out-of-home care, lack of schooling, workplace injury, drug addiction and mental health problems. Luke aspires to being able to work again but is unable to leave his unit unaccompanied due to anxiety. His privately run Supported Residential Unit in Melbourne, is advertised as an aged care facility. Although Luke spent some time in kinship care he wishes he'd had a mum and dad there to support him. He did not have a leaving care plan as his last placement in out-of-home care was with a relative, so it was assumed that he could stay on in that placement (Snow, Mendes, & O'Donohue, 2014).

This is just one story of many where young people do not have a planned transition to independence starting at 15 years of age. The discussion of whether a young person is able and interested in staying on with their carer is critical to planning for secure accommodation post care. If the placement breaks down after they turn 18 years old they are often left with few or no supports and no awareness of how to access appropriate accommodation. With transition planning, the range of life needs can be discussed and planned for, including safe and secure accommodation and who to turn to when young people need help, ensuring they have at least one responsible adult who cares, who they can turn to if they need support or someone to talk to.

In regard to mental health planning, young people have identified that the post care phase can be challenging and cause deterioration in their mental health (CREATE Foundation, 2014). Mental health for young people who have been in out-of-home care can be a complex issue that is impacted and shaped by the neglect and/or trauma that brought children and young people into out-of-home care and then by the experiences in care and post care of support, relationships, safety and stability. Transition planning is critical to supporting the mental health of young people, who report that too often mental health services focus on diagnosis and treatment at the expense of engagement. When poorly managed this can exacerbate existing mental health issues leading to a deterioration in mental health while young people are transitioning out of care (CREATE Foundation, 2014).

Child protection and disability systems

As the National Disability Insurance Scheme (NDIS) is progressively rolled out across Australia, it is still unclear to CREATE how it will work for children and young people with a disability who are in out-of-home care, however, the NDIS has the potential to improve the individual tailoring of services to children and young people's needs.

Particular attention needs to be given to children and young people in out-of-home care and the transitions, both life and bureaucratic, that they will pass through. Evidence shows better outcomes for children and young people with a disability where transitions are well supported. Some of the transitions for children and young people in out-of-home care that need to be well planned include:

- educational – entering early childhood settings, changes from kindergarten to primary school, primary school to high school to higher education, changing classes, teachers or schools;
- personal – changing carers and placements;
- life stages – childhood, adolescence, early adulthood, exiting care and moving to independence while being supported; and
- bureaucratic changes – moving from child and adolescent mental health services to adult mental health services, child protection services to disability services, leaving out-of-home care.

The NDIS is about the care of the person and their individual needs to reach their potential in life, therefore it should work better for children and young people as they transition from out-of-home care to independent living. However, if this is not planned and supported, there is danger that care and support may fall away. In her 2013 study, Mitchell (2013) identified the need for improving the interface between out-of-home care services and Disability Services. The systemic problems that already exist for children and young people with a disability in out-of-home care will not be resolved by the introduction of the NDIS without specific planning to improve whatever interfaces will be needed.

Mitchell (2013, p. 41) highlights the problem that “good assessment” doesn’t necessarily translate into access to recommended services for children, family or carers and that “children fell between the cracks of service systems, whether between Ozchild and DHS, between disability and child protection services within DHS, between government departments … or a combination of these”.

To aim for the best possible outcomes for children and young people with a disability in out-of-home care attention must be focussed on improving how child protection and disability support departments and agencies work together. Going forward this applies to the trialling and implementation of the NDIS.

Conclusion

CREATE Foundation commends the Senate Community Affairs References Committee for its focus on the adequacy of residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia. It is timely as it provides the opportunity for input into the redesign of support services for people with a disability through the NDIS to improve the life outcomes for those young people who are in residential care. For young people who may be in out-of-home care now and facing adult life in residential care this Senate Inquiry is an opportunity to find and promote better home-based placement solutions or improve residential care to be more “home like”.

CREATE hopes this Senate Inquiry will provide more evidence of what is happening in the community and what improvements are needed. However, it is likely that more engagement is needed with disability groups and the people they represent to get a better understanding of what is working and what is not working for young people with severe disabilities.

For out-of-home care systems this submission highlights the ongoing need for better planning and support for children and young people with a disability in the transitions they go through both in their personal circumstances, their placements, their education and their health and physical wellbeing. In particular, there is a need for planned and gradual transition to independence, with ongoing support in the years after the young person leaves out-of-home care. This is critical for all young people in out-of-home care and particularly those young people in out-of-home care with severe disabilities who have an ongoing need for government and community services.

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