

13 February 2015

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

community.affairs.sen@aph.gov.au

To the Senate Standing Committee on Community Affairs

Re: Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

MacKillop Family Services (MacKillop) would like to thank the Senate Standing Committee on Community Affairs for considering the issue of younger people with disability in residential aged care. The terms of reference provide a unique opportunity for important issues about young people with a disability and their care and accommodation needs to be considered at the federal level. MacKillop anticipates that recommendations will have a lasting impact and provide guidance for all levels of government and the community sector, providing disability support.

MacKillop provides services to children, young people and their families in Victoria, New South Wales and Western Australia.

MacKillop delivers a range of community programs which provide services to families in which there is a child or young person with a disability. Additionally, MacKillop works with families providing family referral, support and early intervention services, specialist education services and refugee services.

As a provider of disability services in the National Disability Insurance Scheme (NDIS) Barwon, Victoria trial site, we feel we are well placed to provide a perspective on how the National Disability Insurance Agency (NDIA) deals with the complexity of young people with disabilities who require care and accommodation.

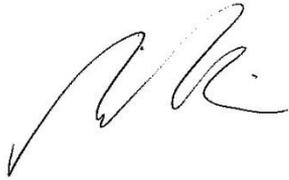
Additionally, we provide out-of-home care to a number of young people with complex needs, including physical disability, intellectual disability and mental health issues. These young people are in state care because of family abuse and other trauma. At present, there is an inadequate response to the needs of these young people. MacKillop's submission is, therefore, informed by our experience providing services to children and young people in the care of their families, in the care of another family or in state care.

MacKillop is of the view that any discussion about the care and accommodation needs of people with disability must be accompanied by a discussion about support for family and carers. Additionally, in MacKillop's experience, people with disability have sometimes experienced trauma, so we advocate for a service system that builds supports that are therapeutic and trauma-informed.

JUSTICE
HOPE
COLLABORATION
COMPASSION
RESPECT

We wish to thank you for the opportunity to contribute to the Inquiry, and look forward to learning of the findings. If you have any queries related to this submission, please contact Dr Nick Halfpenny, Director of Policy and Quality, on 03 9257 2323.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'MC', written in a cursive style.

Micaela Cronin
CEO, MacKillop Family Services

MacKillop Family Services

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

Prepared for the Senate Standing Committee on Community Affairs

Recommendations:

1. Accommodation and support needs are unique therefore accommodation and support should be tailored to the needs of the individual.
2. Case management and support should be family-centred and respond to a range of family needs.
3. Any examination of younger people in aged care must also examine the accommodation and support needs of young people with a disability in state care and the options available to them upon turning 18 years of age.
4. Specialist residential care for young people with a disability should be home-like, promote secure attachment and promote social inclusion and community engagement.
5. Alternative forms of support and care are important and need to be appropriately funded within the NDIS.
6. Consider further research and evaluation into the effectiveness of key worker support and wrap-around support for people with disabilities.
7. Further research is required on the numbers of young people in state care with a disability, and long term outcomes, including accommodation options after leaving state care.
8. Care provided to people with disabilities should be therapeutic and trauma-informed.

A. The estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care

MacKillop has no comment on this issue.

B. Short- and long-term trends in relation to the number of young people being cared for within the aged care system

MacKillop has no comment on this issue.

C. The health and support pathways available to young people with complex needs

In MacKillop's experience, there are two key issues in relation to health and support pathways for young people with complex needs:

1. Accommodation options are inappropriate or inadequate
2. The lack of support for families who wish to care for their family member who has a disability.

Accommodation options

Anecdotal evidence from MacKillop staff suggests there are few options for young people with high needs, and some are inappropriate. For example, some people can access accommodation in which support is provided for example, having meals prepared, but then find there is no personal care. Although support is available, it is inadequate for people with higher needs.

To assist people prepare for living independently, MacKillop (and others) have developed outreach case management responses. MacKillop provides support for young people to develop independent living skills, for example travel training, personal care skills and skills to live with other young people in shared accommodation. However, this is not always an option for people with higher needs.

MacKillop is supportive of accommodation options that provide a range of supports, dependant on an individual's level of need. We have experience providing "cluster" model accommodation for young people in State care, preparing to leave care. The model allows for one-on-one supported living and more independent shared accommodation, on a single site or nearby. Some disability advocates (see, for example, Young People in Nursing Homes National Alliance *Shaping the Future Today: Transforming housing policy for Australians with Disability* 2014) do not support long term cluster

living for people with disabilities as it does not promote community integration and involvement. MacKillop recommends consideration of cluster model type housing as a “stepping stone” to independence for younger people with a disability. It has been successful for young people with a range of needs. MacKillop agrees with the proposition put by the Young People in Nursing Homes National Alliance (YPINH) that new housing must facilitate community connections, over providing strict “models”.¹

Recommendation

1. Accommodation and support needs are unique therefore accommodation and support should be tailored to the needs of the individual.

Case management

Any accommodation support for young people should involve support for the individual and their family, regardless of whether they are living with their family or seeking independence. Case management with families should take a family-centred practice approach. Family-centred case management is effective when it:

- Engages, supports and sustains the family unit
- Works with all members of the family to build on strengths and assist family functioning
- Focuses on the unique needs of individual family members
- Assists families that are at risk of breaking up to remain intact
- Acknowledges and works on complex and interlinked issues (for example, child protection, violence prevention, disability, homelessness)
- Provides individual and family counselling.

When working with families with a child or young person with disabilities, case managers are able to address the risks of family breakdown by responding quickly and strategically to unmet support needs within the family. Case managers can work on building family resilience through family coaching and parenting support. In MacKillop’s view, whether the young person is living with their family, preparing for independence, or living away from family, support for the whole family unit is essential.

Recommendation

2. Case management and support should be family-centred and respond to a range of family needs.

Case example – unique needs unmet².

In 2011 Daniel and Jess, both 30 years of age, had their first child, a healthy baby boy they named Jack

Within two months of giving birth, Jess suffered a stroke, which left her severely disabled. As a new father, with a newly disabled wife, Daniel decided the best option for the family was for himself and Jack to establish a home without Jess.

Jess was referred to MacKillop for support. At risk of homelessness, she required accommodation with live-in support. She was unable to hold or carry him and suffered frequent seizures and therefore was unable to have unsupervised contact with Jack. She did, however, want to live close-by to her child and maintain a relationship with him.

Jess was faced with two housing options, both inadequate. The first option was that she could enter residential aged care, which would provide a high level of care and be in the same neighbourhood as Jack. However, this would mean, having no structured community involvement, care that wasn’t tailored to a younger person’s needs and having access to her child in an environment with people whose average age was 83.

¹ Young People in Nursing Homes National Alliance, *Shaping the Future Today: Transforming housing policy for Australians with Disability*, Young People in Nursing Homes National Alliance, Southbank 2014, <http://www.ypinh.org.au/reports> (accessed 12/2/15) page 6.

² All names have been changed.

The second option was with her parents. They lived some distance from Jack and Daniel so Jess resisted their offer. She felt that if she moved in with her parents, there would be a significant negative impact on her capacity to spend time with Jack.

Sadly for Jess, no suitable accommodation could be found, which would provide her with care and support and allow her to have regular involvement in her son's life. Jess was forced to move in with her parents, aged 62 and 67 years. Although she underwent therapy and regained some physical movement, Daniel was still concerned about Jess being alone with Jack and insisted that her parents always be present when Jack was visiting. The system was unable to support Jess's family to prevent separation, and then unable to accommodate Jess and her unique needs as a young mother with a disability.

D. The appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

MacKillop has no comment on this issue.

E. Alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities

MacKillop has experience operating two kinds of supported accommodation for young people with disabilities. We are of the view that both of these are good options, and should be considered as part of a range of responses, according to individual's unique needs. MacKillop recommends reviewing the document "Shaping the Future Today: Transforming housing policy for Australians with Disability" prepared by Young People in Nursing Homes Alliance³ for further information about housing for people with disability.

Young people in state care

As one of Victoria's largest out-of-home care providers, we have experience operating a broad range of out-of-home care models, including residential homes for young people with a disability. MacKillop also have extensive experience operating general residential care, and are able to make comparisons about the differences between these models, for young people with a disability.

MacKillop operates a residential home that is exclusively for young people with a disability. Outcomes for the young people in our disability specialist residential home have been positive. Young people come to this specialised home after experiencing significant trauma as a child or young person, with their family. As a stepping stone to independence, young people in the home experience routines that are tailored to their needs and participate in more structured activities, including community inclusion and social connection, than they have experienced before.

Workers spend time building the capacity of the young people and working with them to connect with the community and work towards independence. Their care and support is provided by out-of-home care staff who have completed additional training in the area of disability and therapeutic care. In MacKillop's experience, specialist residential care results in the disability issues being at the forefront of the service received. Unfortunately, young people with disabilities in other forms of residential care, do not have similar access to these specialised supports, which can result in them becoming marginalised and socially excluded.

Although MacKillop is of the view that specialist out-of-home care is appropriate for children and young people with a disability, we also acknowledge that some have argued that it is not in the interests of people with disabilities to be marginalised in specialised housing. It is our view that specialist out-of-home care should promote secure attachment, be home-like and promote social inclusion and community engagement to ensure that people with disabilities are not isolated in institution-like settings. Additionally, any young person in out-of-home care is engaged in preparing for their independence, and in a disability specific home, these needs are met.

³ Young People in Nursing Homes National Alliance, *Shaping the Future Today: Transforming housing policy for Australians with Disability*, Young People in Nursing Homes National Alliance, Southbank 2014, <http://www.ypinh.org.au/reports> (accessed 12/2/15)

Conversely, it has been our experience that young people with disabilities placed in general out-of-home care without proper attention paid to placement matching and support are especially at risk and vulnerable to bullying and marginalisation.

Recommendations

3. Any examination of younger people in aged care must also examine the accommodation and support needs of young people with a disability in state care and the options available to them upon turning 18 years of age.
4. Specialist residential care for young people with a disability should be home-like, promote secure attachment and promote social inclusion and community engagement.

Family Options

Family Options is a Department of Health and Human Services (DHHS) funded program, that supports families of people with a disability by providing a choice to share their care responsibilities with volunteer carers. DHHS describe Family Options as providing short term and long term alternative family placements for people with a disability who are unable to live with their own family.

The program is designed for children and young people who have high support needs. Key features of the model include placement with a carer, placement support (with capacity for intensive support) and enhanced financial support to the carers. However, as a model requiring the engagement of volunteer carers, Family Options does not fit neatly into the National Disability Insurance Agency's (NDIA) funding models.

This option can be appropriate for young people up to and over the age of 18 years. Clients who are currently accommodated with MacKillop's Family Options are all over 18 years, but entered their placement prior to turning 18 years.

In MacKillop's experience there is a need for care for children and young people with disabilities that avoids or prevents child protection intervention. Families requiring these services have high needs, including disability, mental health and alcohol and other drug issues. There is evidence to suggest that many families need support when caring for a child or young person with a disability. This may include support to assist parents with behaviour management, short term respite and long term alternative care. It is the case that the needs of families are likely to be unique and require flexible and individualised responses.

However, those that need long term alternative care are overlooked by the current NDIA funding schemes. Additionally, a program like Family Options needs to manage volunteer carer recruitment, assessment, training and support, but individualised funding does not allow for this.

Recommendation

5. Alternative forms of support and care are important and need to be appropriately funded within the NDIS.

F. The options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities

MacKillop advocates for support and appropriate accommodation options for younger people who are “de-institutionalised”, to ensure that people with disabilities aren’t socially excluded. Unless there are adequate supports in place, young people leaving residential aged care are at risk of becoming further marginalised. This should be accompanied by support for families who are seeking to support their young people either at home or in the community.

G. What Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future

MacKillop effectively engages with other agencies to develop seamless responses. In MacKillop’s view, it is the service system, not the client, that is “complex” and the system should be more adept at providing services to people with a range of needs. Models such as “key worker” support and “wrap-around” care should be further explored and evaluated for people with serious and/or permanent disabilities.

Recommendation

6. Consider further research and evaluation into the effectiveness of key worker support and wrap-around support for people with disabilities.

Case example: family-centred wrap-around practice⁴

Alice is 13 years old and has significant mental health issues. Faye, her mother, has an intellectual disability and mental health issues. Alice’s family came to be involved with MacKillop’s Integrated Family Services because of concerns about Faye’s capacity to parent Alice and the younger children. There are fifteen services involved with the family. In consultation with Faye and Alice, a decision was made to try wrap-around support because of concerns about Faye’s mental health, Alice’s mental health and the behaviour of the younger children.

Alice presented, at times, as being very mature and capable of making some decisions about her future. Her key worker advocated for Alice to be involved in the wrap-around support team meeting. It was thought that it would be an empowering process for Alice to be involved and it was decided that she should be able to put her views. Allowing young people to participate in decision making requires reviewing their ability to understand the actions being proposed and their maturity, levels of autonomy and their age. Taking these factors into account, it was decided that Alice should be involved in the meeting.

Before the meeting Alice spoke with her key worker, who explained to her how the meeting would run, the context and the intention of the meeting. To ensure she was able to participate fully, she was given the opportunity to think about that information and to ask questions.

On the day of the meeting, Alice presented as anxious and agitated. She relaxed after the round table introductions and when she realised that her views were going to be taken seriously by the group and but that decisions would be made in her best interests.

Alice made a significant contribution to the discussion. She listened to the concerns of some of the professionals and expressed that she did not agree and that some of the professionals had, in her view, not made an accurate assessment of her needs. She then explained her needs, as she saw them, to the group. Alice’s participation in the meeting was empowering for her, as it gave her a sense of control over what would happen next in her life. It also helped her to understand the roles of all the professionals involved, and who she could call on for what support.

⁴ All names have been changed.

H. The impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation

MacKillop has experience providing services in the Barwon, Victoria, trial site and our experience has indicated that the scheme works well for those who can articulate their needs and wants. However, there are some barriers to access for those with intellectual and mental health disabilities. Additionally, some young people in State care and their case managers are not receiving information to assist them.

Additionally, very few Culturally and Linguistically Diverse (CALD) families are linked in with the NDIA. Diversitat has identified that only small numbers of their newly arrived clients in the Barwon region have accessed the NDIA to seek information about eligibility.⁵

MacKillop staff working with families have identified that many of them are uncertain about accommodation options for their child as they become more independent. Some are unaware that they may be entitled to funding under the NDIS.

I. State and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care initiatives in improving outcomes for young people with disabilities

MacKillop has no comment on this issue.

J. Any related matters

Out-of-home care – young people with a disability in State care

Alongside the unacceptable numbers of young people with a disability in residential aged care, MacKillop is of the view that the issue of young people with a disability who are in residential out-of-home care is also unacceptable. In our recent submission to the Senate Standing Committee on Community Affairs inquiry into out-of-home care, we noted our concern about the numbers of children with a disability entering out-of-home care. Research suggests a significant percentage of children and young people who enter the out-of-home care system have some degree of disability and are at higher risk of a mental health disorder. This is supported by anecdotal reports from MacKillop staff suggesting the proportion of children and young people in care with a disability is high. However, data on this issue is inadequate. For example, a recent CREATE Foundation report noted that estimates as to the proportion of children and young people in out of home care with a disability range from between four and 60 per cent.⁶

Recommendation

7. Further research is required on the numbers of young people in state care with a disability, and long term outcomes, including accommodation options after leaving state care.

⁵ Diversitat Settlement and Community Programs, *Diversitat Disability Finding Report*, Geelong, 2014
http://www.diversitat.org.au/documents/Diversitat_disability_findings_report_1.pdf (accessed 12/2/15) page 6.

⁶ CREATE Foundation, "Supporting children and young people with a disability living in out-of-home care in Australia: literature review", South Brisbane, 2012

Trauma-informed care

MacKillop is currently implementing the Sanctuary model of care. Sanctuary is a clinical and organisational model which recognises the inherent vulnerability of all individuals and social systems to adversity, loss and change. In confronting this unavoidable aspect of the human condition, the Sanctuary model responds with a core belief that every individual and system has the capacity to transcend this vulnerability and overcome the impact of these potentially traumatic experiences. All MacKillop staff are trained to use Sanctuary tools when working with clients, placing us in the unique position of providing trauma informed care across all our services.

In light of this, in MacKillop's view, it is important to examine intersections between disability and trauma. It is our view that any service providing support, care or accommodation to people with a disability must improve their capacity to ensure that all needs are met. This would require adequate resourcing of services to ensure they are therapeutic and trauma informed and with a disability focus.

In 2008 the Office of the Senior Practitioner (Department of Health and Human Services) in Victoria reported the importance of enhancing awareness of trauma and related interventions across the disability service system through education and training. That report also emphasised the capacity of staff in a range of disability settings to provide secure attachment relationships noting that, "in addition they need to ensure that residential and other environments are safe, predicable and promote development and exploration."⁷

MacKillop is of the view that residential aged care, and any alternative care systems for people with disabilities must be cognisant of the pervasive nature of trauma, and provide staff and systems that are trauma-informed and care that is therapeutic.

Recommendation

8. Care provided to people with disabilities should be therapeutic and trauma-informed.

⁷ Office of the Senior Practitioner 2008 "Positive Solutions in Practice: Attachment and Trauma: People with an Intellectual Disability"