Transforming Respite: an example of youth engagement

BY THE MINISTRY OF HEALTH'S DISABILITY SUPPORT SERVICES

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The Office of the Children's Commissioner promotes the participation of children and young people in decisions that affect them. When done well, it upholds their right to have a say and be heard, it advances the best interests of children and young people and produces better decision-making overall. We endeavour to model best practice for engaging children and young people, as well as encouraging other organisations to do the same. Find more case studies on our website www.occ.org.nz

Introduction

Disability Support Services within the Ministry of Health developed a strategy to improve how families are supported to have a break (respite) from caring for a disabled family member. Children and young people make up around 70 per cent of disability respite service users.

We engaged with children and young people with disabilities to hear their perspectives on respite. We are using the information shared by young people to:

- provide feedback to providers about what children and young people tell us about respite
- inform quality improvement of current respite services
- inform development of a respite outcomes evaluation framework.

To find out more about the Ministry of Health's respite services see: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite-and-carer-support/respite-services

About the Office of the Children's Commissioner

The 1.1 million children and young people under 18 make up 24% of New Zealand.

The Children's Commissioner Judge Andrew Becroft and his office advocate for their interests, ensure their rights are upheld, and help them have a say on matters that affect them.

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Method

We developed a Children's Engagement Plan based on the information provided on the Children's Commissioner website[1] about how to engage with children.

The original methodology we selected was to hold focus groups at special schools with children with disabilities. Feedback from special schools was that many of their students would be unable to engage with us directly due to being non-verbal and having multiple and profound disability. This required us to design an alternative approach which included:

1. Teacher assisted interviews with young people with high and complex needs
2. An online survey for children and young people with autism
3. Feedback from the Cerebral Palsy Society Youth Alliance Working Group

Outcomes

Our engagement with children and young people with disability found that their current experiences of respite are for the most part positive, with some room for improvement. With some exceptions, most young people said they felt safe at respite.

The children and young people we engaged with had intellectual disability, physical disability, autism or multiple and profound disability. The activities that these children and young people want to do while at respite are the same as the activities that most people of a similar age would be likely to want to do (e.g. go to movies, play computer games, go to the park or beach).

The children and young people gave perspectives that had not been captured elsewhere in our discussion with adult stakeholders about respite. The new perspectives offered are that youth desire to:

- establish a supportive community around their respite services
- ensure that their parents are well supported and welcomed within the respite service
- have more of a say about the types of activities on offer at respite and about how the service is run.

1. TEACHER-ASSISTED INTERVIEWS WITH YOUNG PEOPLE WITH HIGH AND COMPLEX NEEDS

Teachers at a special school in Auckland interviewed 12 students aged between 15 and 21 years. All 12 students used respite in some form and had high and complex needs.

ENJOYING RESPITE AND FEELING SAFE

The students were asked if they had fun when they go to respite. Their answers were positive – they enjoyed activities like going to the park and hanging out with their friends. Students said they felt safe while at respite and were happy to go there. One student who spent time with a host family for respite said that the host family was like their second family.

Less positive aspects of respite reported by the students were that it was sometimes noisy and there

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[1] http://www.occ.org.nz/listening2kids/how-you-engage/

were too many people there.

ACTIVITIES AT RESPITE

The students were asked what activities they like to do at respite. Their responses were typical of many teens and included:

- bowling
- shopping
- learning to cook
- going to the beach or park
- playing games
- going for walks
- going to the movies
- playing music

2. ONLINE SURVEY FOR CHILDREN AND YOUNG PEOPLE WITH AUTISM

We asked Altogther Autism[2] to help us convene focus groups with children and young people with autism to discuss their respite experiences. The advice from Altogether Autism was that children and young people with autism would engage more readily with an online survey than with face to face communication. We designed an online survey in consultation with Altogether Autism and it was shared on social media from 1 to 9 June 2017.

We received 93 responses in total, but 44 were incomplete or from adults– some of these responses were perhaps parents having a look at the survey before passing it on to their children to complete.

There were 49 responses from people aged under 20 years. Because the purpose of the survey was to hear the youth voice on respite, we have included only the responses from people aged under 20 years in this analysis. The views of adults have been captured elsewhere in the respite strategy development process.

Of the 49 responses from children and young people, 27 said that they used respite or got looked after by someone that is not their parent or guardian. The most common types of respite used was to be cared for by an extended family member or family friend.

RESPONSES BY AGE, GENDER AND LOCATION

The age of respondents ranged from four to nineteen. The average age was 12 years, and the median was 13 years.

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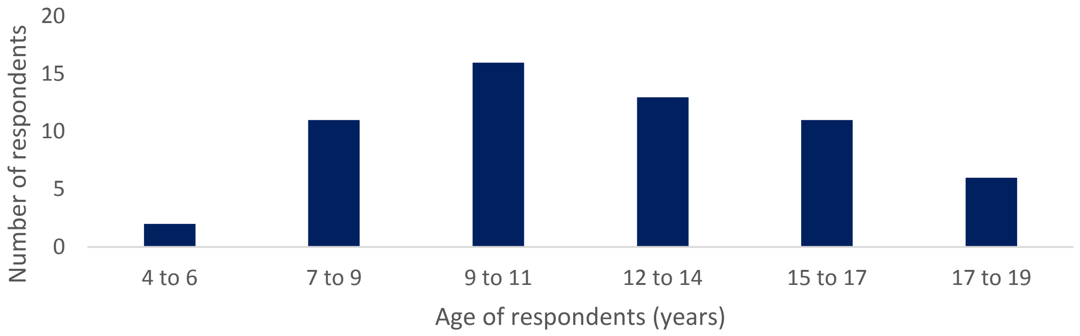
[2] A nationwide autism spectrum disorder information and advisory service.

AGE OF SURVEY RESPONDENTS (YEARS)



Of the 49 responses, 36 identified as male, 12 as female and one trans female. Forty responses were from the North Island (17 were from Auckland). Nine responses were from the South Island.

ENJOYING RESPITE AND FEELING SAFE

The survey asked 'Do you enjoy respite?' There were 35 people who answered this question. Most (85%) said that they enjoyed respite or enjoyed it sometimes. Two young people said they did not enjoy respite and three were not sure.

We asked whether the children and young people felt safe at respite. There were 34 responses to this question - 70 percent answered 'yes'. Three people said they sometimes felt safe – their reasons included that the staff were not trained to understand autism. Three people said they did not feel safe. Four people were unsure.

ACTIVITIES AT RESPITE

The survey asked "Please tell me three activities you would enjoy doing at respite". There were 21 responses to this question. The responses were:

- Watching movies
- Playing Xbox or Playstation
- Swimming
- Going to the park/for a walk/ bushwalk/ beach
- Sports/ dancing
- Horse riding/ cycling/ go karts
- Lego/ puzzles/ games
- IPad, computers
- Playing/ hanging out with other kids
- Cooking/ Baking
- Art
- Helping (with tasks around the house or garden)
- Maths
- Shopping
- Music
- Going out for a meal

QUALITY IMPROVEMENT

The survey asked 'What would make respite better for you?' The improvements that children and young people would like included:

- respite being located closer to home
- being able to interact more with their peer group – being with people they know and like

- having better activities on offer and being able to choose what to do
- having support workers that they know, are caring and understand autism.

3. FEEDBACK FROM THE CEREBRAL PALSY SOCIETY YOUTH ALLIANCE WORKING GROUP

The Cerebral Palsy Society established a Youth Alliance Working Group which met in October 2016 to discuss youth perspectives on respite.

The group considers that the current problems with respite include that:

- it can be a negative experience with no access to the natural environment, no activities and no say in how the service is run (including what time you are put to bed)
- it is not designed for youth, it's sterile, not a warm environment
- support workers need better training.

The group's vision for the future is that:

- children and young people have a say in what they do while at respite
- lots of activities are available
- respite is a community of good friends, a place you want to go
- the respite community is also a support network for parents
- the people working there love what they are doing and are empathetic
- respite is a place to build independence and transition to living away from the family home.

The Cerebral Palsy Society supports changing the term 'respite' to something more welcoming.

What we learnt

This engagement with youth was on a small scale and was undertaken as part of much wider engagement with the disability sector as part of the respite strategy development process.

Engaging with youth enabled us to test whether our ideas for the future would be acceptable for children and young people.

From a process perspective, the lessons we have learned included:

- understanding the value of taking advice from sector experts to inform our engagement methodology
- being adaptive with our engagement methodology and responsive to how the target community wants to be engaged with
- creating the space for youth-led groups to design their own ways to give us feedback
- allowing more time and avoiding school holiday periods when undertaking youth engagement
- the need to approach a number of sector groups to achieve hearing the views across the sector and having feedback from enough people.