

**Disabled Children:**

**Voluntary Out-of-home Placement Review**

Summary of Consultation Findings

November 2015



DISABLED CHILDREN PROJECT

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**Acknowledgements**

The Ministries of Social Development and Health would like to thank all the people who took time to share their views, insights and experiences with us as part of the consultation for the Disabled Children: Voluntary Out-of-home Placement Review.

We sincerely hope that when those who participated in the consultation read this report, they will feel that we have provided a balanced representation of the range of different viewpoints.

We would also like to acknowledge and thank those individuals and organisations who helped us to publicise and promote the consultation. Without our help we would not have got such a great response.

Special thanks to members of the Disabled Children Project Working Group from the disability sector who have shared the journey with us from when the Review was first set up in early 2014 and who made it all possible.

**Summary of Consultation Findings**

**Background to the disabled children: voluntary out-of-home placement review and consultation**

1. We are reviewing the way in which children with severe disabilities are placed in out‑of-home care under the Children, Young Persons, and Their Families Act 1989 (CYPF Act). As part of the review we are also looking at ways services can better respond when families are having difficulty sustaining care for disabled children at home.
2. The focus of the review is on disabled children who are, or are likely to be, voluntarily placed in out-of-home care by their parents under sections 141 or 142 of the CYPF Act.
3. Of the more than 10,000 children and young people aged under 17 years receiving Ministry of Health Disability Support Services, at any one time fewer than 50 are likely to be in out-of-home care under sections 141 and 142 of the CYPF Act. But they are amongst the most vulnerable of children.
4. The Government asked for this review to be carried out as part of the programme of work coming out of the 2013 Vulnerable Children Bill and the subsequent 2014 Vulnerable Children legislation.
5. The review is action 6(d) under the Disability Action Plan 2014-2018 which describes it as:

*“A review of the current care and support process for disabled children who are (or are likely to be) subject to care under the Children, Young Persons, and Their Families Act 1989 be initiated to establish whether disabled children and their families are being treated equitably and fairly, and in their best interest, and if not, provide advice on changes needed to legislation, operational policy, operational delivery and or monitoring and enforcement.*

1. In February 2015, Cabinet agreed to undertake public consultation to contribute to the review. Consultation was carried out between 18 March and 29 May 2015.
2. Through the consultation process we heard from a wide range of individuals, families, organisations and groups with experience or interest in supporting disabled children, either in their home or in out-of-home placements. This report summarises the findings from the consultation.

**Promoting and conducting the review**

1. The key stakeholders identified for the review and consultation are:

* disabled children and young people who are, or have been, cared for in out‑of‑home residential or foster homes under section 141 or 142 of the CYPF Act
* families, whānau and carers of severely disabled children
* advocacy and support groups and organisations in the disability sector
* non-government organisations providing out-of-home placements for disabled children
* non-government organisations providing support and services to families caring for severely disabled children at home
* professionals and organisations employed or funded by Government to work directly with severely disabled children and their families
* others with a particular interest in the review.

1. We promoted the review and the consultation through:

* the [Disabled Children Project](https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/disabled-children-project/in-home-support-and-voluntary-out-of-home-placement-review.html) webpage (accessible through the Ministry of Social Development website), and notices on the Ministry of Health and the Office for Disability Issues websites
* networks, communications and publications of the Ministries of Social Development and Health, and the Office for Disability Issues
* Disabled Person’s Organisations (DPOs) and their networks[[1]](#footnote-1)
* Disabled Children Project Working Group members sharing information through their organisations and networks.[[2]](#footnote-2)

1. We used the following consultation techniques and materials, including web‑publishing:

* a comprehensive public consultation document in PDF and Word format. This provided background information about the review and included 11 questions for people to respond to
* a short form submission document with the consultation questions
* publishing an Easy Read version of the consultation document for people with learning disabilities, low literacy levels and English as a second language
* an audio video and a New Zealand sign language video on the Project webpage which provided information about the review and the consultation questions
* an online survey of the consultation questions which could be completed through the Project webpage
* setting up a closed Facebook group for people to join and post comments
* establishing a cell phone and landline number that people could call to get more information or make an oral submission.

1. We also held regional forums in Auckland (two forums), Christchurch, Wellington and Hamilton.

**Consultation themes**

1. The consultation was centred on 11 questions based around four key themes that had emerged from an initial workshop with key stakeholders held on 27 June 2014 in Wellington.
2. The four themes were:
3. support to families with severely disabled children (3 questions)
4. out-of-home placements for disabled children – the legislative framework (2 questions)
5. out-of-home placements for disabled children – services and support (4 questions)
6. transitions from out-of-home placements (2 questions)

**Public input through submissions and regional forums**

1. People made use of the different ways available to have input through the consultation period as set out below:

|  |  |
| --- | --- |
| **Consultation options** | **Number of people** |
| written submission | 35 |
| online survey | 37 |
| oral submission by phone | 2 |
| email submission to the Project Team | 2 |
| attend a regional forum | 50 |
| comments posted on Facebook | 5 |
| *Total* | *131* |

1. While most of the submissions were made by individuals, a number were made collectively by groups of health professionals, including eight from groups of doctors and clinicians in various District Health Boards.
2. Set out below is a breakdown of the types of submitters where this is known. Submitters had the option of remaining anonymous by not including their personal details in their submission. Group submissions are counted as one submission in the table below.

| **Category** | **Number of submissions** |
| --- | --- |
| 1. Parents with a disabled child (either being cared for at home or in a residential placement under section 141 of the CYPF Act) | 22 |
| 1. Individuals with experience of a section 141 placement | 1 |
| 1. Non-government organisations providing support and services to disabled children and their families (e.g. in-home support, respite care, residential care under section 141 and professional bodies) | 14 |
| 1. Individuals with experience of, or have family / friends who are, caring for disabled children | 8 |
| 1. Health professionals (including paediatricians and clinical supervisors) | 16 |
| 1. Advocacy Groups (Human Rights Commissioner, Children’s Commissioner and Complex Care Group) | 3 |
| 1. Anonymous | 12 |
| 1. Mixed groups (including Facebook and regional forums) | 6 |
| *Total* | *82* |

1. Most of the submitters who identified their locations came from the North Island (29). Of these, the largest number came from Auckland (9), followed by those from or near Hawke’s Bay (including Napier, Hastings and Gisborne) (8). There were 11 submitters from the South Island, with half coming from Christchurch (6). Thirty-six submitters did not specify their location.
2. Attendees at the five regional forums (Wellington, Hamilton, Auckland (two forums), and Christchurch) included parents with disabled children, non‑government organisations providing support and services to disabled children and their families, and some representatives from advocacy organisations.

**Donald Beasley Research – the views of disabled children**

1. We were especially keen to hear from disabled young people who had experience of being in a section 141 out-of-home placement. However, we only received one submission (an email) from a young person who had been placed in out-of-home care under section 141.
2. To ensure the views of young people are included in the review we have commissioned the Donald Beasley Institute (DBI) to interview 12 to 15 disabled young people who have recently left a section 141 placement.
3. DBI will be carrying out interviews during October/November, and reporting on their findings by 7 December 2015.

**Approach to analysing submissions and notes from regional forums**

1. As a result of the different ways people made submissions, we used qualitative and quantitative text analysis to capture all opinions and ideas as robustly as possible.
2. We used a process for grouping the information received through the consultation into common categories based around responses to the eleven consultation questions in the consultation document. The common categories were then broken down by topics represented by themes and sub-codes. The frequency by which respondents referred to these topics and a number corresponding to the submitter’s name were recorded in a database.
3. The submission analysis process enabled us to describe the common ideas that emerged from the consultation. It also provided an approximate indication of their ‘popularity’ (that is, how frequently they were raised in submissions and by participants at regional forums). For coding purposes each regional forum was treated as a submission, as was the closed Facebook group.

**Reporting the findings**

1. This report conveys the consultation findings as accurately and neutrally as possible. We have not added our own interpretation or assessment of the consultation findings beyond reporting the common themes that emerged through the consultation. We have used this approach because we believe it is important to relay what was important to submitters.
2. We have included quotes from submissions in this report. In many cases, the submitter’s own words best convey the lived experiences, challenges and struggles many of these families and the professionals and organisations working with them face on a day-to-day basis.
3. We have contained the length of this report by only including topics which more than five submitters commented on.

**Feedback from the consultation**

1. Set out below are the key findings from the consultation based on the 11 consultation questions grouped by each of the four themes.

***Theme one: support to families with severely disabled children***

*QUESTIONS: We want to know:*

*1.1 if families caring for a severely disabled child at home are having difficulties accessing existing support and services available to them and, if so, why this is?*

*1.2 what is working well in terms of supporting families caring for a severely disabled child at home?*

*1.3 about anything else you think would make it easier for these families*

***1.1 Accessing existing support and services***

1. Submitters noted that the first step to access services to help families sustain care for a disabled child at home is to understand what is available.
2. Twenty-six submitters[[3]](#footnote-3) reported it can be very difficult for families to know what support is available that might help them. This was seen by many of these submitters as a major barrier to services being delivered in a timely manner. At the Auckland forum it was noted that language and communication (eg literacy) can be a problem for parents caring for a disabled child, especially if they have a disability themselves, or if English is not their first language.
3. Attendees at the Christchurch regional talked about how, in their view, there was a need for someone to help families access information about what supports are available, such as a key worker.
4. Ten submitters[[4]](#footnote-4) expressed that a positive relationship between parents and service providers/professionals was crucial for achieving positive outcomes. Ten submitters[[5]](#footnote-5) also commented on the importance of family support to maintain care in the home.
5. Submitters mentioned the challenges which often arose as result of different expectations and attitudes between parents and professionals and organisations. Eighteen submitters[[6]](#footnote-6) felt that the process parents faced in determining their eligibility for services was adversarial.

***1.2 What is working well in terms of supporting families***

1. Thirty eight submissions[[7]](#footnote-7) noted the value of respite services to give parents time off from caring for a disabled child. However, many submitters noted gaps in the provision of respite care services across the country. Families were not always able to use the respite allocated to them because there was no suitable provider available. Some submitters felt more emergency respite and weekend respite care in particular was needed. Concerns were also raised about the quality of the services that are available, and it was suggested that there needed to be more skilled carers and respite staff. Twenty one submitters[[8]](#footnote-8) spoke of the importance of behavioural support for sustained care of severely disabled children in their family home. This support was considered critical to manage challenging behaviour.
2. Twenty three submissions[[9]](#footnote-9) noted the value of early intervention to prevent families reaching a point of crisis. Attendees at the Auckland forum talked about the difficulties in picking the point at which early intervention would have the most impact. However there are predictable transition times that can become crisis points, for example when children turn five and start school and preschool support services such as Well Child/Tamariki Ora, also when children reach adolescence.
3. Submitters noted a range of other services they valued which were provided by the Ministry of Education and the Ministry of Health. These included the Intensive Wraparound Service, Individualised Funding, education support, mental health support for the child, and training for providers and families.

***1.3 What would make it easier for these families***

1. Ways identified by submitters to make it easier for families include better access to services that meet the needs of children including culturally appropriate services, navigators or case-workers for families, more funding for disability support services, caregivers and foster care, better service co-ordination and flexibility in the use of services, more financial assistance for families with a disabled child.

**Graph 1: What would make it easier for families to care for their disabled child?**

***Theme two: out-of-home placements for disabled children – the legislative framework***

*QUESTIONS: we want to know:*

*2.1 If we were to create a new voluntary out-of-home placement process for disabled children within existing resources, what would this look like and who would be involved?*

*2.2 are there any other changes we could make to the CYPF Act that you think would improve the system for providing out-of-home placements for severely disabled children?*

***2.1 Improving the process for out-of-home placements***

1. Submitters referred to the added stress for families making the difficult decision and then going through the placement process. As one non-government organisation put it:

*“The process of a s141 or s142 [placement] could be more family friendly. For families to sit in a room full of professionals and say they are unable or unwilling to look after their child is traumatic. Even more so if the child in question is in the room and understands this.”*

1. The following were suggested to improve the process for voluntary out-of-home placements: improve the timeliness and transparency of the current process for accessing out-of-home care, ensure disabled children’s views are taken into account, and appoint an advocate for the child.
2. Submitters spoke of the need for specialist skills to ensure children’s views are taken into account in the process. Many commented on the limitations of achieving this with some of these children, hence the emphasis on appointing an advocate for these children as illustrated below.

*“Some children will never have the ability to have 'their say' as a direct result of their disability. They can however have an appointed advocate whose responsibility is the child's welfare and best interests, as much as that is possible to determine on an individual level. Otherwise, on a basic human rights level, children who cannot make their needs and wishes known should have every possible opportunity afforded to them to communicate as much as possible what can be determined as their wishes. By this I am referring to communication aids, interpreters etc.”* (Health professional)

**Graph 2: What would improve the process for out-of-home placements?**

***2.2 Making changes to the Children, Young Persons, and Their Families Act 1989***

1. Some submitters were in favour of repealing sections 141 and 142 of the CYPF Act, others were against it, and some thought it could be repealed as long as other checks and balances were incorporated in the legislation.
2. Nine submitters[[10]](#footnote-10) recommended the current sections 141 and 142 of the CYPF Act should be repealed. These submitters supported repeal to promote the best interests of the affected children through:

* establishing equitable treatment for all children under the legislation (ensuring there are the same limitations on voluntary care arrangements as for other children in care)
* providing in legislation for disabled children in care the same rights and protections, including advocacy, legal representation, review, and external oversight of a care placement as non-disabled children
* reframing the situations where disabled children have both care and protection needs, so that these are responded to as they would be for non-disabled children.

1. Submitters considered that if sections 141 and 142 were repealed, disabled children in need of extended out-of-home-care could be placed under the same sections of the CYPF Act as children in care for mainstream care and protection reasons.
2. Concerns expressed about repealing sections 141 and 142 focussed on:

* whether it would be in the best interest of disabled children and their families
* whether Child, Youth and Family is sufficiently equipped and resourced to effectively provide care for disabled children
* the effects on parents of disabled children having to work with Child, Youth, and Family to have their child cared for outside of their home (this was linked with the perceived stigma in having dealings with Child, Youth, and Family).

***Theme three: out-of-home placements for disabled children – services and support***

*We want to know:*

*3.1 Is there something we could do differently to protect the rights and interests of disabled children while they are in out-of-home placements?*

*3.2 What do you think makes an out-of-home placement successful for the disabled child and the disabled child’s family and whanau?*

*3.3 What makes it easier for family and whanau to have regular contact with their disabled child while they are in an out-of-home placement?*

*3.4 About any other suggestions you may have about how we could improve the process and system around out-of-home placements.*

***3.1 Protecting the rights and interests of disabled children in out-of-home placements***

1. Twenty-two submitters[[11]](#footnote-11) commented on the need for a human or child rights perspective[[12]](#footnote-12). Many of these submitters were concerned the current process and practices did not give practical effect to the rights of these disabled children. Suggestions included: adequate safeguards that are child centred and grounded in the children’s human rights; and processes that uphold children’s right to life in a family (if not their family of origin, than in a foster family).
2. Seventeen submitters[[13]](#footnote-13) included comments regarding the safety of disabled children when they were either being cared for at home, or when they were in an out-of-home place.
3. Some parents felt they could not ensure the safety of their child in their home because of the child’s behavioural difficulties relating to their disability put them and other family members at risk of harm. An example given was a child who was fascinated by water but did not understand the risks between water and electrical appliances and, so needed constant supervision.
4. To ensure the safety and the suitability of the placements, regular monitoring was seen as essential in 26 submissions[[14]](#footnote-14). Independence in the monitoring of placements and a process to follow-up and make improvements was often mentioned.

*“3-6 monthly review meetings with the staff and other agencies involved to ensure that all needs of the child are being respected and met.”* (Parent with disabled child)

1. One submitter (an advocacy group) states that:

*“Disabled children in residential care are an especially vulnerable group and at high risk of unhelpful or harmful practices. There should be regular independent oversight of services provided to such children.”*

***3.2 Factors that make a placement successful***

1. The following were raised in submissions as being factors important to increasing the success of placements:

* safety was a significant factor in how parents evaluated the suitability of out‑of‑home placements
* high quality staff with professional skills and the ‘right attitudes’ (29 submitters)[[15]](#footnote-15)
  + *“Staff and carers need to have understanding of the disability and knowledge and skill at managing difficult behaviours.”* (Parent with disabled child)
* placements need to be as home-like as possible (10 submitters)[[16]](#footnote-16), creating a nurturing, kind or loving environment to ensure the child’s well-being (12 submitters)[[17]](#footnote-17)
* placements should be therapeutic and restorative, rather than permanent, with the intention of return home or to a placement in the community of origin
* good communication between the parents and the provider of an out-of-home placement
* placements that are close to the family’s home (28 submissions)[[18]](#footnote-18). Close by placements are valued by parents as it gives them confidence they can check in on their child regularly and ensure they are safe and well. Distant placements were seen as a serious barrier to families having a positive relationship with their child, and greatly reduced any chance of the child returning home.

*”The out-of-home placement needs to be close to where the family are living and they still remain active participants in facilitating the care provided. The placement needs to enable whanāu to come and go freely, stay over, meet and socialise.”* (Anonymous)

* development plans must be in place and carried out (18 submitters[[19]](#footnote-19))

*“In my residential service I have very much appreciated them allowing me to be as independent as I can by providing me with a bus concession card, a gym membership, and also they provided me with swimming concession card. I've really enjoyed having the chance to become an independent knowledgeable young man, and endeavour to achieve in my aspirations. I appreciated the time and availability that the Trust have put into encouraging me to get involved in many of the aspects of my life that I'm involved in, which ensured the availability of funds and transport to get to these activities."* (Disabled child with experience of a section 141 placement)

* placements need to be able to provide a complete package of supports for the child (15 submitters[[20]](#footnote-20)).
* consistent routines - *stability and routines in a placement to help children feel secure and safe (10 submitters).[[21]](#footnote-21)*

*“For autistic children there is a need for a caring environment which is predictable and stable. Routines are very important and they are often upset by unexpected events.”* (Individual with experience of caring for disabled children)

1. Submitters did not advocate for residential facilities as a preferred place for severely disabled children over foster care, but 15 submitters[[22]](#footnote-22) thought there was a role for residential facilities (this is linked with the belief that some children could not be cared for within foster care).
2. Other submitters strongly supported children being raised either by their families or in a family environment (9 submitters)[[23]](#footnote-23).

*“The only option should be biological parents, or other parents willing to take this on. It is not appropriate for vulnerable disabled children to be in residential services. They deserve to have primary carers.”* (Anonymous)

1. Some submitters[[24]](#footnote-24) wanted more choice of out-of-home placements for their children. Eleven submitters[[25]](#footnote-25) commented on the limited choices available for out-of-home placements. They said that often in their region there was only a single provider of placements. Eight submitters[[26]](#footnote-26) expressed concern about the lack of transparency in some of the placement options offered.

*“Families need more choices for placements. Often there is only one option and so the families are forced to take that one or keep the child at home. There should be options that families can look at and make an informed decision.”* (Non‑government organisation)

***3.3 Ensuring children have regular contact with their family and whānau***

1. Thirty submitters[[27]](#footnote-27) emphasised the importance of regular contact between the family and the child. This was highly valued by parents, and seen as important for maintaining identity for the child when away from their home. Maintaining contact would be supported by:

* a written contact plan which is monitored to ensure relationships are being maintained (4 submitters[[28]](#footnote-28))
* transport allowances to cover travel and accommodation costs for families/parents where the placement was out of region (19 submitters[[29]](#footnote-29))
* family holidays with the disabled child to maintain contact (14 submitters[[30]](#footnote-30))

***3.4 Other suggestions for improving the process and system around out‑of-home placements***

1. In relation to considering out-of-home placements, 20 submitters[[31]](#footnote-31) observed parents felt negatively judged in making this decision. It was consistently repeated in submissions that the decision to place their child in care was not made lightly, and was a difficult point for families to reach.

***Theme four: transitions from out-of-home placements***

*QUESTIONS: we want to know:*

*4.1 what could be done to protect the interests of disabled young people during transition?*

*4.2 what do you think could be done to improve how the transitions from out-of-home placements are managed?*

***Improving transitions from out-of-home placements***

1. Thirteen submitters[[32]](#footnote-32) recommended increasing the age of providing care under the Act, and making it consistent with other legislation that affects these disabled young people.
2. Twelve submitters[[33]](#footnote-33) noted the importance of early planning to ensure good outcomes for young people transitioning into adult services. Many of these submitters did not believe this was currently happening to an adequate standard.

**Other issues raised in submissions**

1. Ten submitters[[34]](#footnote-34) spoke about the relationships between government agencies and how this could be fraught. This was commonly the relationship the Ministry of Health had with either Child, Youth and Family or the Ministry of Education. The common complaint related to stand-offs over funding but also involved disputes over eligibility.

*“It can be difficult to distinguish between care and protection, and disability issues, or both may be present … It remains a source of enormous frustration to clinicians and families when there are both care and protection and disability issues and agencies cannot reach agreement over who will fund the placement. I have seen these disagreements compromise outcomes for children and embarrass both agencies.”* (Advocacy group)

1. A number of submitters mentioned problems families experience getting schools to accept their disabled child, and provide the additional support that is needed to ensure they are safe at school, and able to engage in the classroom.
2. Another submitter (a health professional) talked about how stand downs and exclusion from school may be factors precipitating a request for out-of-home placement.
3. Eleven submitters[[35]](#footnote-35) referred to the importance of providing supports in schools for disabled children to be able to attend mainstream schools in their community and continue to live with their families. One submitter (a parent) said more teacher aide funding to provide appropriate support during school was needed so that children could continue to be cared for at home.
4. Other submitters supported the provision of separate specialised schools for some children.
5. Ten submitters[[36]](#footnote-36) referred to the need for after school care and holiday programmes that are equipped to cater for their child’s needs. As one submitter (a parent) put it:

*“Parents are desperate for a modest level of after school care so they can stay in the workforce. Just try and get it for a disabled child and the door is slammed in your face! No parent should be disadvantaged like that for keeping their child at home.”*

**Summary of key findings**

1. The family situation and the support and services families received while caring for their disabled child at home were the most significant issues for the majority of submitters, based on the information provided in their submissions.
2. A summary of key findings from the consultation is set out below:

| **Themes** | **Summary of key findings** |
| --- | --- |
| 1. Support to families with severely disabled children | Parents can experience difficulties accessing information on what services and support are available to them.  A significant group of submitters referred to the importance of the family’s relationship with professionals, and how this was crucial for achieving positive outcomes. Some felt the process for accessing services was adversarial for parents.  A significant number of submissions included comments about the perceived inability of local services to meet the needs of high end (i.e. severely) disabled children. This was particularly so outside the main centres.  Respite care, behavioural support and early intervention support and services were the most commonly mentioned service types that were needed by families to enable them to continue to care for their child at home, but not always available.  Appointing a navigator or case worker to help families to access services; better service co-ordination; and more flexibility were mentioned as factors that would make it easier for families to care for a severely disabled child at home.  More financial support for families who have a disabled child was suggested as a way to help these families meet the extra costs of caring for their child, such as meeting the costs of repairs of property damage.  Wider concerns were expressed about the adequacy of funding for disability services in New Zealand, and the level of pay for skilled carers of high needs children. |
| 1. Out-of-home placements for disabled children – the legislative framework | Submitters’ concerns with the current process included delays, a lack of transparency, and confrontational relationships between parents and decision-makers.  Many submitters commented on the importance of understanding the child’s view in the out-of-home placement process.  There was overwhelming support from submitters for an independent advocate for the child when entering an out‑of‑home placement, with just under half of this group of submitters thinking this role should be performed by legal counsel.  The majority of submitters did not directly comment on the legislation. Nine submitters recommended repealing sections 141 and 142 of the Children, Young Persons, and Their Families Act 1989, two opposed repeal, and two suggested amendments. |
| 1. Out-of-home placements for disabled children – services and support | Significant groups of submitters commented on the importance of children’s rights in accessing out-of-home placements, the importance of ensuring the child’s safety, and the regular monitoring of placements, and children’s rights to a family life.  A close location, choice of options regular contact with their family, having well trained staff, and regular monitoring were the four most commonly mentioned aspects of good placements. Stability and routines in placements was also mentioned to help children feel secure and safe.  A number of submitters thought that residential facilities have a place, but others considered that children should always be raised in a family environment. One submitter stated that placements should be therapeutic and restorative, rather than permanent.  Many submitters emphasised the importance of regular contact between children and families. To facilitate this, a number recommended transport allowances for families, and some suggested that written plans for maintaining relationships should be in place. |
| 1. Transitions from out-of-home placements | A significant group of submitters thought the age that care agreements ended should be increased from 17 to align with when education services end for severely disabled children (21 years) to protect the interests of young people transitioning from out-of-home placements.  Early planning for transitioning was also mentioned as a way to improve the process. |
| Other issues raised in submissions | Some submitters talked about the fraught relationships between government agencies, and the negative impact this had on outcomes for children and families.  Problems with access to learning in schools near a child's home was cited as a significant driver in parents seeking out-of-home placements for a child.  Access to suitable school holiday programmes and after school care for disabled children is needed t support parent's employment and meeting siblings needs. |

**Next steps**

1. The consultation findings, together with research that is currently being carried out by the Donald Beasley Institute on disabled children’s experience in out-of-home placements, will form the basis of advice to government on options for changes to policies, practices and legalisation that will address submitters’ key concerns and lead to better outcome for disabled children and their families.
2. Information on any changes agreed by Government will be posted on the Disabled Children Project webpage.
3. Information gained through the consultation process about improvements that could be made in areas not covered by the review will be passed on to the appropriate ministries to respond to.



### APPENDIX B: Donald Beasley Institute Research Report

1. The national DPOs in New Zealand are the Disabled Persons Assembly New Zealand; People First New Zealand; Deaf Aotearoa; Blind Citizens New Zealand; Balance NZ; Deafblind New Zealand; and Ngāti Kāpo O Aotearoa Inc (Ngāti Kāpo) [↑](#footnote-ref-1)
2. The Project Working Group includes representations from two DPOs (Ngāti Kāpo and the Disabled Persons Assembly New Zealand); Parent to Parent; IDEA Services and CCS Disability Action. [↑](#footnote-ref-2)
3. Three parents, seven NGOs, three individuals, six health professionals, two anonymous submitters, five mixed groups. [↑](#footnote-ref-3)
4. Three parents, one NGO, one individual, two health professionals, one advocacy group, and one anonymous submitter, and one mixed group. [↑](#footnote-ref-4)
5. One parent, the young person with experience of a s 141 placement, three NGOs, three health professionals, and two anonymous submitters. [↑](#footnote-ref-5)
6. Eight parents, two NGOs, three individuals, two health professionals, and three mixed groups. [↑](#footnote-ref-6)
7. Ten parents, nine NGOs, three individuals, ten health professionals, one advocacy group, two anonymous submitters, and three mixed groups. [↑](#footnote-ref-7)
8. Four parents, five NGOs, ten health professionals, and two mixed groups. [↑](#footnote-ref-8)
9. Three parents, eight NGOs, one individual, seven health professionals, one advocacy group, and three mixed groups. [↑](#footnote-ref-9)
10. Four NGOs, three health professionals, one advocacy group, and one anonymous submission. [↑](#footnote-ref-10)
11. Five parents, seven NGOs, three individuals four health professionals, two advocacy groups, one mixed group. [↑](#footnote-ref-11)
12. The relevant instruments are the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of Children (UNCROC). These instruments include the right of disabled children being able to live with their family or in a family like environment (UNCROC Article 9), and the right of disabled children to have their views taken into account in decisions affecting them (UNCRPD, Article 7 and UNCROC Article 12). [↑](#footnote-ref-12)
13. Nine parents, three NGOs, two individuals, one health professional, one anonymous submission, one mixed group. [↑](#footnote-ref-13)
14. Five parents, six NGOs, two individuals, ten health professionals, one advocacy group, two anonymous submissions. [↑](#footnote-ref-14)
15. Seven parents, seven NGOs, two individuals, nine health professionals, two advocacy groups, two anonymous submissions. [↑](#footnote-ref-15)
16. Two parents, three NGOs, one individual, two health professionals, and two anonymous submissions. [↑](#footnote-ref-16)
17. Four parents, the person with experience of a section 141 placement, two NGOs, one individual, one health professional, one advocacy group, one anonymous submission, one mixed group. [↑](#footnote-ref-17)
18. Ten parents, seven NGOs, two individuals, seven health professionals, two mixed groups. [↑](#footnote-ref-18)
19. Two parents, five NGOs, one individual, seven health professionals, two anonymous submissions, one mixed group. [↑](#footnote-ref-19)
20. Four parents, five NGOs, three health professionals, one advocacy group, two mixed groups. [↑](#footnote-ref-20)
21. Two parents, two NGOs, one individual, two health professionals, one advocacy group, one anonymous submission, one mixed group. [↑](#footnote-ref-21)
22. Six parents, three NGOs, six health professionals. [↑](#footnote-ref-22)
23. Three parents, one NGO, two individuals, two health professionals, and one anonymous submission. [↑](#footnote-ref-23)
24. Five parents, two NGOs, three health professionals, one mixed group. [↑](#footnote-ref-24)
25. Five parents, two NGOs, three health professionals, one mixed group. [↑](#footnote-ref-25)
26. Three parents, two NGOs, two health professionals, one mixed group. [↑](#footnote-ref-26)
27. Fourteen parents, five NGOs, four health professionals, one advocacy group, four anonymous submissions, two mixed groups. [↑](#footnote-ref-27)
28. One parent, one NGO, three health professionals. [↑](#footnote-ref-28)
29. Six parents, four NGOs, one individual, six health professionals, two mixed groups. [↑](#footnote-ref-29)
30. Seven parents, three NGOs, one individual, two health professionals, one advocacy group. [↑](#footnote-ref-30)
31. Six parents, two NGOs, five health professionals, two advocacy groups, one anonymous submission, four mixed groups. [↑](#footnote-ref-31)
32. Two parents, four NGOs, one individual, five health professionals, one anonymous submission. [↑](#footnote-ref-32)
33. One parent, four NGOs, one individual, four health professionals, one anonymous submission, one mixed group. [↑](#footnote-ref-33)
34. One parent, two individuals, two health professionals, one advocacy group, two anonymous submissions, two mixed groups. [↑](#footnote-ref-34)
35. Three parents, two NGOs, three health professionals, one advocacy group, and two mixed groups. [↑](#footnote-ref-35)
36. One parent, the person with experience of a section 141 placement, three NGOs, two health professionals, and three mixed groups. [↑](#footnote-ref-36)