Disabled children: voluntary out-of-home placement review

Public Consultation Document

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DISABLED CHILDREN
PROJECT

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Review of the care and support system for disabled children who are, or are likely to be, placed in out-of-home care voluntarily by their parents under the Children, Young Persons, and Their Families Act 1989

Overview

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 the support and services offered to severely disabled children and their families so they can be cared for at home where this is possible and so mitigate the need for such placements.

We are doing the review to explore with the sector, and children and their families what they think needs to change to ensure disabled children have the same rights as other children to live in a family environment. If disabled children are unable to live with their own family, we want to find out what changes are needed to provide an effective system that:

- works in the best interest of the child
- ensures that the disabled child's best interest is always at the centre of decision-making about where they live
- ensures the right safeguards are in place to protect the interests of the disabled child, and that they are not treated in a way that disadvantages them because of their disability
- supports the disabled child to have a say and participate in decision-making about where they are going to live.

The Government has asked for this review as part of the programme of work coming out of the Vulnerable Children Bill and the subsequent 2014 Vulnerable Children legislation.

Scope of the review

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 a care agreement through section 141 or 142 of the CYPF Act. This is referred to as 'the disability pathway' to out-of-home care placements.

The review covers:

- the Ministry of Health, district health boards and Child, Youth and Family (which is part of the Ministry of Social Development) policies and practices for providing out-of-home placements for severely disabled children under the disability pathway
- CYPF Act care provisions as they affect this group of disabled children and their families
- the provision of government funded disability and social support services to sustain families caring for severely disabled children at home.

Out of scope for the review

For this review, we will not be looking at:

- the care and support of non-disabled vulnerable children
- the care and support of children and young people whose level and nature of disability means they do not (or would not) meet the criteria for out-of-home placements under the disability pathway. See page 16 for a description of the level of disability covered by sections 141 and 142 of the CYPF Act
- the care, support and out-of-home placements of disabled children and young people who come into care under other parts of the CYPF Act. This includes, for example, if they have been abused or neglected or have been arrested
- ACC's policies for disabled children.

There is more information about the review and the scope on pages 13 and 14 of this consultation document.

Public consultation

The public consultation for the review will take place from 18 March 2015.

The last date for receiving feedback or submissions will be 29 May 2015.

There is information about how you can be part of this review on pages 7 to 11.

Foreword

Karanga karanga karanga ra, karanga ki te ata hāpara e tohungia nei te rangi hou, tēnei te reo e karanga nei, tēnei te reo e mihi nei, tēnei te reo e kawea ra ngā wawata o tēnā o tēnā o tātou kua whetu rangitia. Heoi anō, moe mai rā i te rangimārie nōreira moe mai moe mai moe mai rā.

Piki ake piki ake ko te reo pōwhiri ko te reo whakatau, ko te reo e kotahi ai ko kāpō, ko turi, ko hauā. He reo kōrero he reo wānanga he reo whakarite kia tū te ao e tūmanakohia ai.

Nō reira ka tuku atu tēnei reo kia rere ai i ngā hau e whā, e rere e rere e rere rā! Ki mai koe ki ahau he aha te mea nui o te ao? Māku e ki atu, he tangata he tangata he tangata e!

As we direct our collective voices to call to the dawn, to signify the coming of a new day, the voices who call, the voices who greet, the voices who carry the dreams of those who dwell in the heavens like the stars which decorate the night sky, we acknowledge your contribution, so in your memory we bid you eternal peace.

We extend our voices of welcome and friendship using the united voice of the disabled community of Aotearoa New Zealand. This voice, which is speaking, this voice of collaboration, will create pathways to an accepting world.

We send forth this voice to the four winds, to take flight and be heard! Ask me, “What is the greatest thing in the world?” I will reply, “It is people, it is people, it is people!”

[source: New Zealand Disabled Person’s Organisations Report to the United Nations Committee on the Rights of People with Disabilities on New Zealand’s Implementation of the Convention on the Rights of Persons with Disabilities – July 2014][1]

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[1] http://www.dpa.org.nz/store/doc/DPO%20Shadow%20Report.pdf

On 26 September 2008, New Zealand ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Convention makes it explicit that States must ensure the full realisation of all human rights and fundamental freedoms for all disabled people, on an equal basis with others, and without discrimination of any kind on the basis of disability.

On 8 April 2014, the Ministerial Committee on Disability Issues approved the Disability Action Plan 2014-2018. This Plan progresses the CRPD. Action 6(c) of the Disability Action Plan directs that:

> *"A review of the current care and support processes for disabled children who are (or 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."*

In May 2014, the Ministries of Social Development and Health set up this Project and established our Project Working Group to ensure that the interests of disabled children and their families were well represented in the review.

Our Project Working Group comprises of representatives from the Ministry of Social Development (including Child, Youth and Family), the Ministry of Health, the Office for Disability Issues, disabled persons organisations (the Disability Persons Assembly NZ and Ngāti Kāpo O Aotearoa Inc.), CCS Disability Action, IHC (IDEA Services) and Parent to Parent. We are responsible for the direction of the Project and formalising the development of options and advice.

Our long-term vision for disabled children is that:

> *"Disabled children are safe, strong and thriving and live with families and whānau wherever this is possible."*

If disabled children are in residential placements, we want these to be family type environments and for children, families and whānau to remain connected.

We want disabled children to be able to voice their views on what they want their lives to be like and for families and caregivers to be able to seek help when they need it.

We want agencies and organisations working with disabled children and their families to be able to provide an integrated, timely and appropriate response to disabled children and their families.

We have written this public consultation document to generate discussion within our communities and to invite you to have your say. We want to know what is working, what is not, and what needs to change in the existing system of providing support and services for disabled children and their families.

We can only influence change with your input.

We look forward to receiving your feedback and input through this consultation process.

Chrissie Cowan, Executive Officer, Ngāti Kāpo o Aotearoa

On behalf of the Project Working Group

Disabled Children Project

Have your say

Have your say on what the Government could do to get better results for severely disabled children who are (or are likely to be) put in out-of-home care voluntarily by their parents through a care agreement under section 141 or 142 of the Children, Young Persons, and Their Families Act 1989 (the CYPF Act). In some cases this is foster care with a family, but in the main, it is care in small residential homes operated by non-government community organisations.

We want feedback from a wide range of individuals, families, organisations and groups who have personal experience of, or are involved with, providing support and services to disabled children, either in their home or in out-of-home placements.

We are especially keen to hear from:

- 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
- other interested parties.

Your input through the consultation process will be used by the Project Working Group to inform advice to the Government on how we can better use our resources and what changes could be made to legislation, policy and practices to get better results for disabled children, their families and whānau (there is more information about the Project Working Group on page 15).

About this consultation document

This document contains information about the review of the current support and placement system for severely disabled children who are (or are likely to be) placed in out-of-home care voluntarily by their parents through the ‘disability pathway’ (this is section 141 or 142 of the CYPF Act).

The consultation document includes a brief description of the group of severely disabled children who are, or have been, in out-of-home placements under the disability pathway.

The second part of the consultation document sets out four key themes where improvements in the current system could be made. These themes have emerged through submissions to the Vulnerable Children Bill and from a preliminary stakeholder workshop held in early 2014.

For each theme, there is a description of the relevant part of the system for providing out-of-home placements. We have also included a summary of what people have already told us about what they see as the issues for disabled children and their families. There are also some of their ideas on how we could improve the current system.

There are a number of questions at the end of each theme that we would like your response to. A summary of all the questions can be found at the back of the document (pages 35 and 36).

What we want to hear from you

We want to know what you see as the issues with the current system of providing services and support to sustain care for severely disabled children within their families and, when this is not possible, the system for providing out-of-home placements under sections 141 and 142 of the CYPF Act.

We also want to know what you think is working well and how we can build on this.

We are especially interested to hear your ideas about how we can make the system work better – for severely disabled children, families, whānau, carers and professionals.

How to respond

You can make a written or online submission, or have input through the social media sites set up for this purpose from **18 March 2015.**

The closing date for making a submission or providing feedback is **29 May 2015.**

You might want to give feedback by answering the questions relating to each theme in this document. Please feel free to make any additional comments or use a different format if you want. You do not have to answer all or any of the questions or provide personal information if you do not wish to.

Any information you do provide will only be used by the Ministries of Social Development and Health to work together with the Project Working Group to develop options for changes to legislation, policies and practices which will then be put forward to the Government to consider.

You can respond to the questions and/or let us know any other thoughts or ideas you have by:

- completing an online survey at www.msd.govt.nz/disabled-children-project
- writing to us at:
  The Disabled Children Project
  Ministry of Social Development
  PO Box 1556
  Wellington 6140
- emailing us at dcp@msd.govt.nz
- phoning us on 029 650 0602 or 04 931 2395 and asking us to post out information to you
- posting comments via social media – check out the Disabled Children Project website for more information on how to do this www.msd.govt.nz/disabled-children-project
- participating in one of the consultation events in your area. Details of these will be posted on the Disabled Children Project website.

Information to include in your feedback or submission

In your feedback or submission it would be helpful if you could include the following:

- your name, address, contact number and/or email address
- whether you are responding as an individual or an organisation/group
- how many people have had input into your feedback
- your particular interest in the review. For instance, if you are a parent or carer of a severely disabled child, a child or young person with a disability who is, or has been, placed voluntarily in out-of-home care, or a person or an organisation providing support or services to a disabled child and their family
- whether you are willing for someone working on the review to contact you to talk about your submission or feedback.

Confidentiality

We will conform to the requirements under the Privacy Act 1993[2] during the review process and will protect your privacy at all times.

Release of submissions

Your submission may be requested by an individual or organisation under the Official Information Act 1982[3]. If this happens, the Ministry of Social Development is obligated to release your submission to the person or organisation who requested it.

If you are making a submission on your own behalf instead of on behalf of an organisation please mark on your submission whether you would like your personal details to be removed if an Official Information Act request is made. Your personal details are your name and contact details and any other information that may identify you.

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[2] http://www.legislation.govt.nz/act/public/1993/0028/latest/DLM296639.html
[3] http://www.legislation.govt.nz/act/public/1982/0156/latest/DLM64785.html

Need more information?

If you have any questions or require any further information about the review, check out the Disabled Children Project website www.msd.govt.nz/disabled-children-project or email us at the Ministry of Social Development dcp@msd.govt.nz

The Ministries of Social Development and Health will be holding a range of events to gather feedback throughout the consultation period from 18 March to 29 May 2015.

Details of these events will be posted on the Disabled Children Project website.

If you want to know about how the review is going, you can visit the Disabled Children Project website where we will be posting regular updates.

About the disabled children: voluntary out-of-home placement review

The vulnerable children legislation

The Vulnerable Children Bill was passed on 1 July 2014. This led to the vulnerable children legislation and changes to the CYPF Act.

Some of the changes to the CYPF Act are aimed specifically at improving the lives of disabled children. They will help to address some of the concerns people have raised about the care of disabled children.

Placements of children in voluntary out-of-home care now have to be reviewed annually. It has been reinforced in the legislation that out-of-home placements must be a last resort.

You can find out more about the vulnerable children legislation on the New Zealand Legislation website where there's a copy of the Vulnerable Children Act[4] and the Children, Young Persons, and Their Families (Vulnerable Children) Amendment Act[5]. Sections 28 and 29 of the Amendment Act specifically refer to changes that affect disabled children.

The review

While the changes in the vulnerable children legislation are a good start and will go some way to improve outcomes for disabled children, the Government feels that we can do more. That's why they've asked for this review to be carried out, and why we're asking for your ideas.

A commitment to carry out this review is set out as a specific action in the latest Disability Action Plan 2014-2018[6] which states we will:

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[4] http://www.legislation.govt.nz/act/public/2014/0040/latest/DLM5501618.html

[5] http://www.legislation.govt.nz/act/public/2014/0041/latest/DLM6110501.html

[6] http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan/index.html.

> *"Review the current care and support processes for disabled children who are (or are likely to be) subject to care under the Children, Young Persons, and Their Families Act 1989 to establish whether they are being treated equitably and fairly, and in their best interests and, if not, to provide advice on changes needed to legislation, operational policy, operational delivery and/or monitoring and enforcement."*

Carrying out this review now means we can build on and support other changes that are either already underway or are planned across government that will better support vulnerable children, including disabled children.

At the end of the review we will be able to identify options for possible legislative, policy and practice changes to improve outcomes for these disabled children and their families.

The scope of the review

There is some information on page 1 about the scope of the review. An overview of what is in and out of scope is also provided below.

In scope for the review

This review is about severely disabled children who are, or are likely to be, voluntarily placed in out-of-home care by their parents through a care agreement under section 141 or 142 of the CYPF Act. These sections of the Act are referred to in this consultation document as the 'disability pathway' to out-of-home placements (page 16 sets out the different definitions of 'disability' used in sections 141 and 142 of the CYPF Act).

We want to better understand the needs of these disabled children. We want to know how families can be supported to care for their disabled children at home wherever possible and so potentially reduce the need for out-of-home placements.

In those situations where families cannot care for disabled children at home, we want to look at the process by which out-of-home placements for these children are provided.

Out of scope for the review

In this review we are not looking at the situation of disabled children who have been abused and neglected. These children can come into care through the care and protection process. They will generally have court orders relating to their custody and guardianship and have Child, Youth and Family involved in their lives[7].

We will also not be looking at the policies and practices of ACC or the Ministry of Education that affect severely disabled children.

The approach we are taking to carry out the review

We want to give effect to Article 4 of the United Nations Convention on the Rights of Persons with Disabilities[8], which has been ratified by New Zealand.

Article 4 requires the Government (as a state party) to closely consult with, and actively involve, disabled people, including disabled children, through their representative organisations.

Undertaking this consultation process as part of the review is one of the ways we will be involving people and organisations in the disability sector in the formation of policies and practices that affect them.

The other way is through the Project Working Group which has been established to oversee the Disabled Children Project and provide advice and direction for the review.

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[7] Child, Youth and Family has work underway to look at how outcomes for all children who come into care can be improved as part of its Strategy for Children and Young People in Care. http://www.cyf.govt.nz/cyf-newsletter/awhi-mai-awhi-atu-issue-3/childrens-action-plan-brings-good-things-for-children-in-care.html

[8] http://www.cyf.govt.nz/cyf-newsletter/awhi-mai-awhi-atu-issue-3/childrens-action-plan-brings-good-things-for-children-in-care.html. http://www.un.org/disabilities/convention/conventionfull.shtml

The Project Working Group

The Disabled Children Project is being led by a cross-agency Project Working Group which includes representatives from:

- the Ministry of Social Development (including Child, Youth and Family; the Office for Disability Issues; and Child, Family and Community Policy)
- the Ministry of Health (including Disability Policy and Disability Support Services)
- non-government organisations in the disability sector including:
  - two representatives from disabled people's organisations (the Disability Persons Assembly NZ and Ngāti Kāpo O Aotearoa Inc.)
  - representatives from each of the groups/agencies Parent2Parent, IDEA Services, and CCS Disability Action.

The Project Working Group brings together people who are directly involved with providing support, information and services to disabled children and their families. They know about the struggles these families can face.

All members of the Project Working Group are involved in the consultation process. They have had input in developing this consultation document, and they will be involved in some of the focus groups and workshops that we will be running as part of the consultation process.

Outcome of the review - options for change

At the end of the consultation process and once we have looked at all the information we have received, we will be advising Government on the changes that could be made through legislation, policy, processes and practice to improve outcomes for disabled children and their families.

We will provide that advice to Government on options for change around **August 2015.**

Any changes the Government agrees to make will begin to be introduced soon after that in **2015 – 2016.**

How do sections 141 and 142 of the CYPF Act work, and who do they apply to?

The level of disability covered under the CYPF Act

Most disabled children can be cared for at home by their parents and, with a bit of extra help, engage in many ordinary activities that children their age do. For children with severe disabilities the limitations on ordinary activities may be greater, and other options for providing day to day care may need to be considered.

Section 141[9] of the CYPF Act describes the level of disability where an out-of-home placement under that section may be considered the best option for a disabled child.

Section 141 states that it should only apply in cases where a child or young person is so mentally or physically disabled that suitable care can be provided only if they are placed in the care of an organisation or body approved by the Ministry of Social Development to provide care for such a child or young person.

This definition of disability is used by Ministry of Health contracted needs assessors and district health boards to determine whether a disabled child meets the criteria to be considered for a Government funded out-of-home placement under section 141 or 142 of the CYPF Act.

Section 142[10] applies to people with a level of physical or mental disability that seriously limits the extent to which they can engage in the activities, pursuits and processes of everyday.

Very few disabled children are placed in out-of-home care under section 142. For this reason we refer mainly to section 141 in this consultation document.

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[9] http://www.legislation.govt.nz/act/public/1989/0024/latest/DLM151029.html

[10] Section 142 refers to the definition of a 'disabled person' in the Disabled Persons Community Welfare Act 1975 (section 2) which is "any person who suffers from physical or mental disablement to such a degree that he is seriously limited in the extent to which he can engage in the activities, pursuits, and processes of everyday life".

Profile of disabled children in section 141 or 142 placements

On 31 August 2014, there were 48 disabled children in out-of-home placements under section 141 of the CYPF Act.

Section 142 is rarely used to place disabled children in out-of-home care, and usually only if a section 141 placement cannot be found.

Here are some facts about disabled children in placements under section 141 or 142 of the CYPF Act from a snapshot taken on 31 August 2014:

- the children were aged from nine to just over 17 years of age. The average age was 14-and-a-half-years
- about 60 percent are aged 15 years and over. Very few (less than 9 percent) are under 10 years
- about 65 percent went into the out-of-home placement at the age of 12 years or above, with the youngest being just over one year of age
- most are male (approximately 90 percent)
- about two-thirds (67 percent) are of European descent and about a quarter (23 percent) identify as Māori. The rest are of Asian descent or their ethnicity is not known
- many have more than one disability. Two of the most common are autistic spectrum disorder (about 40 percent), and intellectual and learning disabilities (43 percent)
- nearly half (48 percent) are in residential facilities provided by Hohepa Hawke’s Bay
- there are a number of other providers of residential care for disabled children across the country, each providing care for between one and five severely disabled children as section 141 placements at any one time.

Sections 141 and 142 disability pathway – brief description

When a family is unable or unwilling to care for a disabled child in the home, they may choose to make private arrangements for their child to be cared for. This could be in a residential facility, in a relative’s home or with a non-kin family.

Where the family seeks State assistance for their disabled child to be cared for outside the family home, and all options to sustain care of the child in the home have been considered, sections 141 and 142 of the CYPF Act may apply.

In practice almost all disabled children who are placed in out-of-home care are placed under section 141 rather than section 142 of the CYPF Act. Section 142 is used in exceptional circumstances only, where a section 141 placement (with a carer approved under section 396 of the CYPF Act) cannot be found.

Also see pages 24 to 29 for a description of the legislative requirements and processes around voluntary out-of-home placements for disabled children.

Themes

Introduction

From previous research, reviews, submissions to the Vulnerable Children Bill and a preliminary stakeholder workshop held in June 2014, we know there are a range of issues relating to the way disabled children come into out-of-home placements that need to be addressed. We have also heard some ideas about how we could respond to these issues.

At the same time, there have been some significant improvements made to the way services and support is offered to severely disabled children and their families over the last few years. These include new Behaviour Support Services, the Wrap Around Intensive Individualised Support and Enhanced Individualised Funding – which give more control and flexibility to families caring for disabled children in the supports they can purchase. We want to know if these improvements are working and making a positive difference.

Most importantly, we want to hear your opinion of what else could be done to make the system work better for everyone – including professionals working directly with disabled children and their families and, especially, for disabled children and their families and whānau.

The issues and possible solutions that have already been identified are set out in this consultation document, grouped around four key themes that have emerged so far. These are:

Theme one:	Support to families with severely disabled children	pages 21-23
Theme two:	Out-of-home placements for disabled children - the legislative framework	pages 24-29

Theme three:	Out-of-home placements for disabled children - support and services	pages 30-32
Theme four:	Transitions from out-of-home placements	pages 33-34

There are a set of questions for you to consider responding to at the end of each theme and a list of all the questions on pages 35 to 36.

There are other ways you can have input into the review – see pages 7 to 11 for more information. You can also check out the online options for responding on the Disabled Children Project webpage www.msd.govt.nz/disabled-children-project

Theme one: Support to families with severely disabled children

We know parents and carers want to look after their disabled child and keep them within their family or whānau wherever possible and that they may need help to do this.

We want to know what support and services make a difference for families caring for a severely disabled child at home and what else could be done to support these families.

The current situation

A number of different government agencies are responsible for providing support and services for families caring for a disabled child at home. This includes Disability Support Services[11] (part of the Ministry of Health), ACC, district health boards, the Ministry of Education and the Ministry of Social Development (which includes Child, Youth and Family). Which agency provides support depends on the cause and type of disability or disabilities the child has.

The Ministry of Health contracts organisations providing Need Assessment and Service Coordination services[12] to work with disabled people to help identify their needs and outline what disability support services are available to them. These services allocate Ministry-funded support services and assist with accessing other support.

Whānau, parents and others caring for a disabled child at home may be eligible for financial help through Work and Income.

There is also a range of community-based social services available that are mostly free for users. Community Investment (part of the Ministry of Social Development) has an online Service Directory[13] of social services available by area.

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[11] http://www.health.govt.nz/your-health/services-and-support/disability-services

[12] http://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services

[13] http://www.familyservices.govt.nz/directory/

Strengthening Families[14] is another way families can access co-ordinated services from a range of agencies that will enable them to care for their disabled child at home.

There are also community support groups and advocacy groups such as Parent2Parent[15] and CCS[16] that provide help and advice to parents and other carers of disabled children.

While social services are important, often it is the support of family, whānau, friends and others with similar experiences in the community that can make the biggest difference for parents caring for a disabled child at home.

The issues

While support and services are provided out in the community, sometimes what families need is not available when, where or to the extent they need it. Or it might be that they just do not know what support is out there.

People have told us that:

- there is a need for better information on, and access to, a range of services and support for families with severely disabled children
- if families could get better support from agencies early before they reach crisis point, they may be able to sustain providing care for a disabled child at home
- there is a lack of transparency and consistency about what services are funded, and for whom
- sometimes services only become available once a crisis with the family has developed.

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[14] http://www.strengtheningfamilies.govt.nz/

[15] http://www.parent2parent.org.nz/

[16] http://www.ccsdisabilityaction.org.nz/

Possible options

Set out below are some ideas and suggestions we have heard from people about how to improve the support currently offered to families caring for a severely disabled child at home.

For example, these are to:

- have one central point where families with a disabled child could go to for information about what services and support are available in their area
- ensure there is more focus on, and funding for, providing early support for families caring for a disabled child at home to prevent where possible the need for out-of-home placements
- provide some sort of community support role/worker to ‘walk alongside’ the family and help the family get information, support and additional help.

Questions

We want to know from you:

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 that you think would make it easier for these families.

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

Even when support is provided in the home, parents and whānau will sometimes make the difficult decision to seek out-of-home care for their severely disabled children because they feel it is the best, or only, option.

We want to know if changes should be made to improve the way in which disabled children are placed in out-of-home care, with the agreement of their parents under section 141 or 142 of the CYPF Act (the disability pathway) and other relevant parts of the Act.

The current situation

When all other options have been exhausted, parents and the organisation providing Needs Assessment and Service Coordination services may decide to place a disabled child in out-of-home care facilitated through the Ministry of Health's Disability Support Services. Formal agreements are then made under section 141 or 142 of the CYPF Act.

Current guidelines[17] recommend that section 142 should no longer be used. Under section 142 children can be placed in adult residential placements which are seen as inappropriate for disabled children.

Section 141 allows for an out-of-home placement with an organisation approved under section 396[18] of the CYPF Act to provide care for disabled children and young people.

In the next section there is a summary of the key points about the process relevant to this theme. There is also a diagram of the process at the end of this document (Appendix A).

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[17] http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/child-and-youth-disability-projects/guidelines-supporting-children-and-young-people-disabilities

[18] Under section 396 of the CYPF Act, the Chief Executive of Child, Youth and Family can approve "any organisation or body whether incorporated or unincorporated" as a Child and Family Support Service. Such approval may be granted.

Processes for decision-making for out-of-home placements

Organisations contracted by the Ministry of Health to provide Needs Assessment and Service Coordination (NASC) services, lead the process and work with the family to arrange for an appropriate out-of-home placement based on the disabled child's needs. Child, Youth and Family co-ordinators then facilitate Family Group Conferences where agreements under section 141 are approved.

The suitability of the placement for the duration of the section 141 placement, and its match to the disabled child's needs, is discussed with their family at all stages of the decision-making process. Children also have a right to be involved (see below).

The process followed for placing a severely disabled child in out-of-home care under section 141 involves several steps.

- Firstly, the Ministry of Health's contracted NASC services[19] organisation, other services supporting the family, and the family themselves will work together to explore what in-home support is available to enable the disabled child to continue to live with their family. They will look at whether the disabled child and their family are using the funded and unfunded support available to them to enable the disabled child or young person to continue to live with their family. This includes natural and community supports as well as funded multi-agency support options.
- If, after considering all available support and services, the family is unable to continue to care for the disabled child at home, a placement in an out-of-home residential facility under section 141 of the CYPF Act will be considered.
- The NASC will complete an assessment of the child with the family.
- If the decision is made to proceed with a section 141 care agreement, the NASC will prepare and submit a placement application to the relevant Ministry of Health panel.

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[19] URL: http://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services

- If the panel approves the application, the NASC works with the family to identify a suitable provider and placement for the child.
- The provider must be certified by a person authorised by the Director General of Health as being appropriate for the child.
- The Ministry of Health panel then reviews the proposed placement for the child. These placements are funded by the Ministry of Health.
- If the funding for the placement is approved by the Ministry of Health panel, the placement is considered at a Family Group Conference. This is convened by a Child, Youth and Family, Care and Protection Co-ordinator under section 145 of the CYPF Act. The family and representatives from the support agencies may attend the Family Group Conference. The NASC attends to confirm approval of the placement.
- The Family Group Conference must thoroughly explore what services and supports are available to maintain the disabled child in their home environment before it can approve a section 141 or 142 care agreement.
- If at the Family Group Conference, everyone agrees to the placement, the NASC co-ordinates the signing of the placement agreement, and the disabled child enters the residential placement.

A flow chart of the section 141 process is provided as Appendix A.

The processes for a section 142 placement are the same as for a section 141 placement, except that under section 142 there is an additional Ministry of Health panel review and the placement does not have to be with an organisation approved under section 396 of the CYPF Act, it can be certified to the Health and Disability Standards to provide residential care for people with disabilities.

When there are also abuse and neglect concerns about the disabled child

Cases where there are abuse and/or neglect concerns about a disabled (or non-disabled) child or young person are referred to Child, Youth and Family. There is information on the Child, Youth and Family Practice Centre[20] and in Appendix B about what happens to all children where there are abuse and neglect concerns under the CYPF Act.

Reviews and renewals of out-of-home placements

The appropriateness of out-of-home placements for each disabled child has to be reviewed regularly. The CYPF Act provides that no agreement under section 141 for any disabled child or young person can extend beyond one year except with approval of a Family Group Conference.

There is no limit, however, to the number of times a care agreement for out-of-home placements can be renewed, provided this occurs through a Family Group Conference and the criteria in section 141 of the CYPF Act are met.

Disabled children’s rights

A disabled young person in an out-of-home placement under section 141 who turns 17 is no longer covered by the provisions of the CYPF Act. Under section 141 care agreements, parents remain the young person’s legal guardian until they reach 18 years.

If the disabled child is aged 12 years or over, under the current legislation they must agree in writing to the making of the section 141 or 142 agreement unless their disability means they are unable to understand the nature of the agreement.

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[20] http://www.practicecentre.cyf.govt.nz/service-pathways/care-and-protection/

Under the principles in section 5(d) and (e) of the CYPF Act, every child's wishes about, and the support for the placement should, where practicable, be taken into account or sought.

There is no legal requirement for the disabled child to have an independent advocate.

The issues

Some people consider that having a separate disability pathway under the CYPF Act means disabled children are treated differently from non-disabled children. They feel this gives disabled children less protection than non-disabled children.

There is concern that:

- children with disabilities can become trapped in residential care because agreements for their care can continue to be renewed (albeit with reviews). By contrast, voluntary care arrangements (sections 139, 140) for children in the care and protection pathway are time limited (either for six or 12 months, depending on the age of the child[21])
- the legislation (sections 141 and 142 of the CYPF Act) does not provide for the appointment of a legal advocate (although there is nothing preventing this happening)
- disabled children need to be supported to be able to take part in the decision-making process to the extent that they are able
- there is no provision made under section 141 or 142 for an external agency to monitor or maintain oversight of a placement[22]. By contrast, children and young people in the statutory care system have social workers to support them. Social workers also monitor and oversee placements.

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[21] There is information on the Child, Youth and Family Practice Centre website about the care and protection pathway.

[22] NASC services are responsible for monitoring and reviewing the support plan for each child or young person on a section 141 out-of-home placement every three months. Services are also regularly audited by the Ministry of Social Development to ensure they continue to meet the Level 1 Standards of Approval for providing placements for children.

- the legislation, policy and practice allows out-of-home placements to effectively become permanent because there is no limit on how many times an agreement under section 141 can be renewed
- it can sometimes be difficult to distinguish between disability issues and care and protection issues for disabled children or young people.

Possible options

Here is what some people have suggested we could do to improve the legislative framework around out-of-home placements.

- Amend the legislation (sections 141 and 142) to:
    - time limit the duration of voluntary out-of-home care agreements and prevent their continued renewal
    - require that an independent advocate is appointed for every disabled child in an out-of-home placement under sections 141 and 142 to make sure their best interests are being considered and met when a placement is being considered or reviewed
    - provide for some form of external oversight of the placement.
- Consider repealing sections 141 and 142 provisions of the CYPF Act.

Questions

We want to know from you:

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?

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

We want to know what services and support can be put in place to make a disabled child's move to an out-of-home placement successful for the child and their family, and ensure they can all stay in contact.

The current situation

A section 141 care agreement must not be entered into if the child's parents, guardians, caregivers or a member of the child's or young person's family, whānau, or family group are unwilling to maintain contact with the child or young person during the term of the care (these requirements are set out in section 147 of the CYPF Act[23]).

Parents continue to be the guardian(s) and make decisions relating to the disabled child while they are in the section 141 placement.

As mentioned in theme two, the CYPF Act provides that no agreement under section 141 for any disabled child or young person can extend beyond one year without the approval of a Family Group Conference. Care agreements for out-of-home placements can, however, be renewed indefinitely, provided this occurs through a Family Group Conference and the criteria in section 141 or 142 and in sections 145, 146 and 147 of the CYPF Act are met.

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[23] http://www.legislation.govt.nz/act/public/1989/0024/latest/DLM151045.html

The issues

People have told us that there are cases where disabled children are put in out-of-home placements when other alternative arrangements could have been made, such as foster care. They believe this contravenes disabled children's rights under the Convention on the Rights of Persons with Disabilities and, in particular, the following articles to the Convention:

> Article 7: which states that "as far as possible, all children have the right to know and be cared for by his or her parents"
>
> Article 23: which states that "children with disabilities have equal rights to family life".

People have also told us that usually care agreements are extended indefinitely and placements are not always properly and/or regularly reviewed.

We do know there are some situations where there is minimal family involvement once the disabled child is placed in out-of-home care. This could be for a number of reasons. In these circumstances, the parents remain the child's guardian(s) and the child can miss out on the opportunity of living with another family in a home environment if the parents do not consent to this.

Possible options

Here is what some people have suggested we could do to improve the system and process around out-of-home placements.

- Change the legislation to require more focus on finding alternative care within the wider family for a severely disabled child who is at risk of being placed on a voluntary basis in out-of-home care.
- Redirect money that would otherwise be spent on providing out-of-home care to fund more use of intensive support packages to support children continuing to live at home or with other family members.

Questions

We want to know from you:

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 for the disabled child’s family and whānau?

3.3 what makes it easier for family and whānau 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.

Theme four: Transitions from out-of-home placements

It is a requirement under the CYPF Act that out-of-home placements are reviewed regularly. An outcome of the review may be that the disabled child returns to their family home or changes placements, depending on their circumstances. However, we know from the data that children seldom return to their family home or change placements.

Transitions to different homes or placements can be difficult and stressful for the young person and their family and whānau and we want to know how to make this process better.

The current situation

As noted in theme two, once they reach 17 years of age, disabled children in out-of-home placements are no longer covered by section 141 of the CYPF Act. Before they turn 17, the NASC work with the disabled young person and their families to support the young person to transition to adult disability services. This includes supported living options and community residential services.

In some circumstances though, disabled young people may continue to stay in the out-of-home placement (usually a group home) after they are 17 and until they are 21. In these cases, all that changes are the contractual arrangement with the organisation providing the placements.

Some organisations providing support for severely disabled children placed under section 141 have a residential school on site where disabled children can remain until they are 21 years of age.

A team focus on the young person throughout the transition process is essential. This involves the young disabled person, their family and whānau, currently involved professionals and others who may become part of the young person's support network in the future. The NASC has a role in working with all involved to ensure a transition plan is agreed upon and appropriate disability supports are co-ordinated.

The issues

One of the reasons transitions can be difficult is because of the number of changes involved. Sometimes not only are disabled young people facing adjusting to a new living environment, some of the services they have been receiving may change.

Often the young person with a disability will have complex needs to consider, so transition planning needs to start early. We know this does not always happen.

We know that some people are concerned about what happens to disabled children once they leave section 141 out-of-home placements.

There is also concern about what happens to disabled children when they reach 17 years of age and section 141 or 142 of the CYPF Act no longer applies to them.

Possible options

It has been suggested that we could improve the process by which transition care plans are put in place by ensuring that in all cases:

- transition plans are done early enough
- the family is involved in the planning
- the young person's views are taken into account
- there is some form of legal representation for young disabled children when they reach 17 years, and before they turn 18.

Questions

We want to know from you:

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

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

Summary of questions

Theme one: Support to families with severely disabled children

We want to know from you:

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 that you think would make it easier for these families.

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

We want to know from you:

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?

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

We want to know from you:

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 for the disabled child’s family and whānau?

3.3 what makes it easier for family and whānau 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.

Theme four: Transitions from out-of-home placements

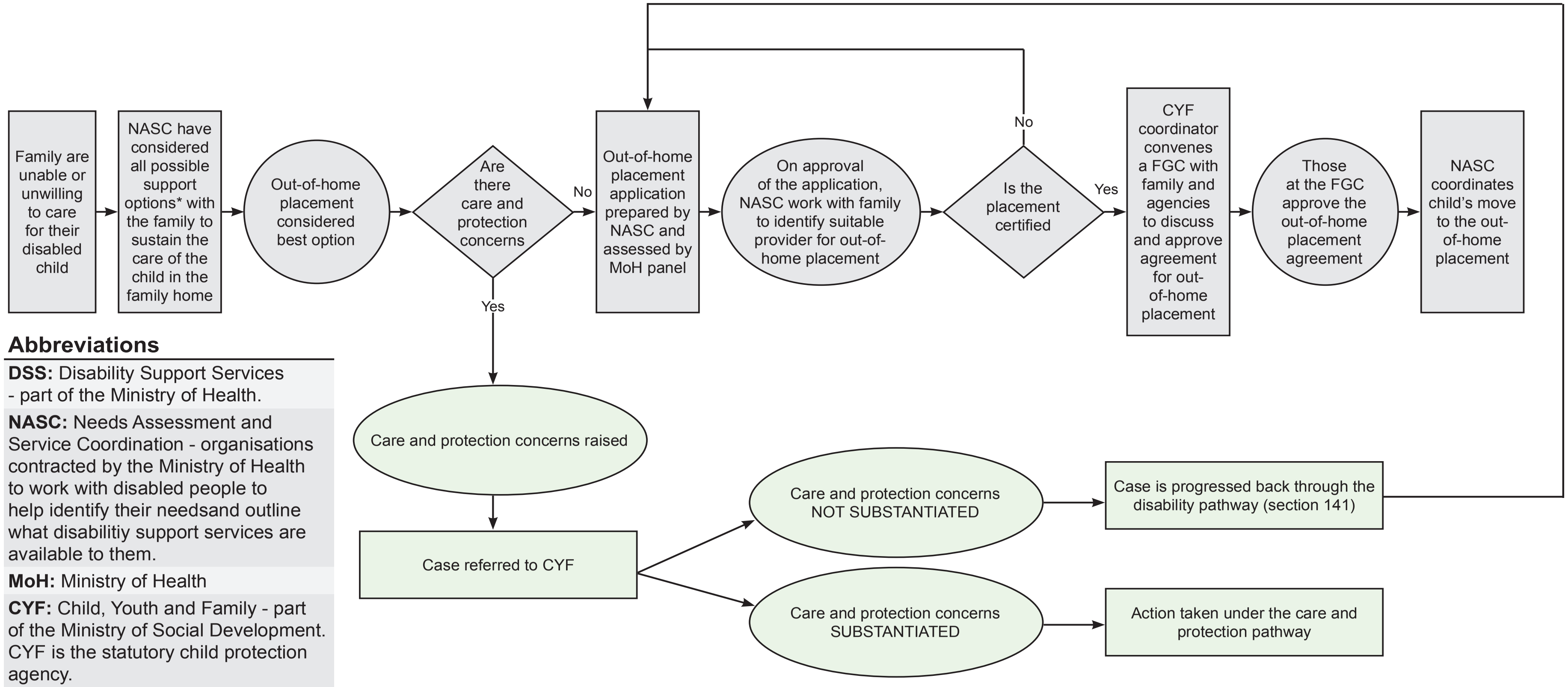
We want to know from you:

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 that transitions from out-of-home placements are managed?

APPENDIX A: Disability pathway

Out-of-home placement process under section 141 of the Children, Young Persons, and Their Families Act 1989



Abbreviations

DSS: Disability Support Services - part of the Ministry of Health.

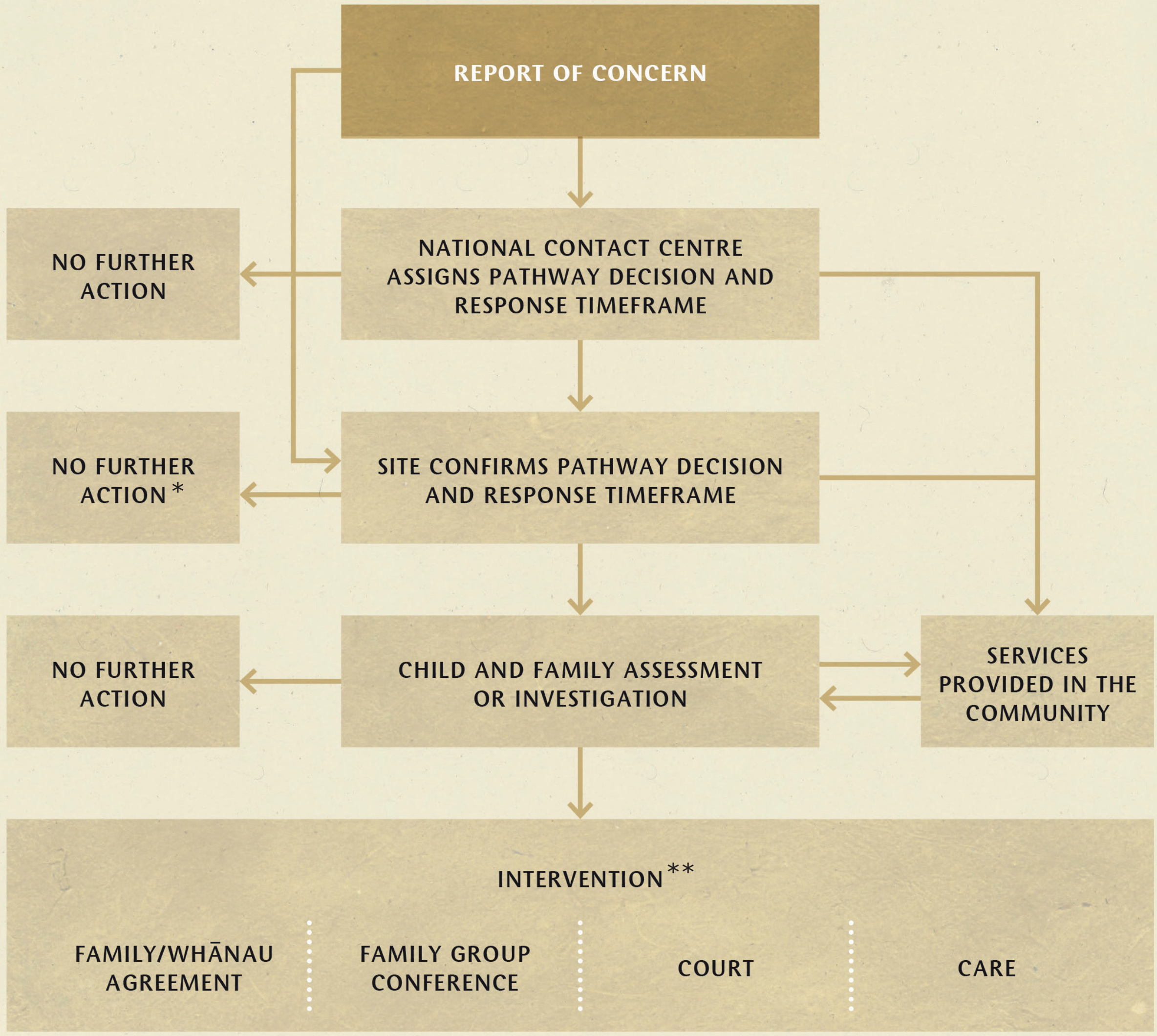
NASC: Needs Assessment and Service Coordination - organisations contracted by the Ministry of Health to work with disabled people to help identify their needsand outline what disabilitiy support services are available to them.

MoH: Ministry of Health

CYF: Child, Youth and Family - part of the Ministry of Social Development. CYF is the statutory child protection agency.

FGC: Family Group Conference. It is statutory requirements that a Family Group Conference must be held before out-of-home care agreement under section 141 can be entered into.

APPENDIX B:
Care and protection pathway



* If care and protection concerns are not substantiated, or no further action by Child, Youth and Family is required, a family with a disabled child may be referred to in-home support services by either Needs Assessments and Service Co-ordination service organisation or Child,Youth and Family, or other options discussed (eg a Section 141 voluntary out-of-home placement)

** An outcome of a Family Group Conference may be an extended agreement for care under section 140 of the CYPF Act if:
- the child or young person is in need of care and protection
- the parent or person who ordinarily cares for the child intends to resume the care of the child or young person by the end of six or 12 month period

Note: These extended care agreements for placing a child in care may be made for up to six months for a child who is seven years old or under or up to 12 months for a child over seven years

DISABLED CHILDREN
PROJECT