



Disabled children: voluntary out-of- home placement review

Submission by New Zealand Needs Assessment Service Coordination Association (NASCA)

Submission Questions

Disabled children and their families often face challenges that other families don't. Some families may need help to care for their disabled children at home.

Question 1

What do you think might help to improve situations where families are having difficulties caring for their disabled children at home and are considering an out-of-home placement under sections 141 or 142 of the Children, Young Persons, and Their Families Act 1989?

Response:

There are a number of service models and systems in place that support families where the children have high and complex disability support needs including Strengthening Families, High and Complex Needs Unit, Special Education services, MSD, allied health services including therapeutic interventions, community social service groups with government contracts, Ministry of Health, Disability Support Services and Needs Assessment and Service Co-ordination agencies who all work with Disabled Children and their families /whanau.

Those people that are involved with children in a professional capacity and are working alongside children with disabilities at times seem to operate from a deficit model and base their views on fixing the problem, rather than living with diversity and embracing that difference. Families / whanau indicate that they would prefer to access information and supports from a one-stop-shop, and to have strengths and abilities of the child and the family acknowledged. They like to be able to be more involved in selecting appropriate services for their children.

While children are younger, early interventions including allied health therapies and schooling are priorities. Gaining the range of supports including education, health, wellbeing of the family/siblings / whanau and social supports for their child across agencies through a central hub would simplify this pathway. Useful options include:

- Home based services which support families with a young child with disabilities who are still living at home, and with a focus on increasing parental competence and resources, on giving emotional support and stimulating the child's development.
- Exploring sharing the parenting to relieve the primary family carers of the day-to-day care

needs of the children whether they have a disability or not, thereby allowing the parents to recharge and then return to the family and all of the associated care needs refreshed.

- Early childhood centres or day care centres, where children with disabilities are included and can access developmental activities, educational support, stimulation and informal play activities with their typically developing peers.
- Before or after school programmes where children with disabilities are included and supported within ongoing programmes. Currently accessing Oscar after school subsidy and after school based programs can be dependent on the situation, willingness and the experience of the staff running the program.
- Behavioral programmes and supports that operate across the home, school and community and are not reliant solely on the families for implementing the programme, for training family and whanau members. Support from hands on mentors for the families to engage and learn how to use the strategies in any setting is required.
- Modifications to homes and their surrounding that meet the family's needs – this includes options that go beyond arrangements for the person with a disability to be contained.
- Access to short term, regular and planned carer support or respite.

The current process requires that children's best interests are prioritised. However, there may be ways to improve and strengthen the focus on children's best interests throughout the decision-making process.

Question 2

What changes do you think might improve the decision-making process for disabled children when they move to an out-of-home placement?

Response:

Nationally, there are memorandum of understanding protocols to combat silos and operational service delivery. At the coal face this message appears to have been lost and Child Youth and Family services staff appear to apply the care and protection framework less rigorously with respect to children and young people with disabilities. Working collaboratively by sharing resources and information can reduce the silo effect and will achieve a collective impact.

In our view CYF's existing structures and legislation could support the pathway for out-of-home placements for all children including those with disabilities without the need for Sections 140 – 149 CYP&F Act.

Sections 140 – 149 CYP&F Act fails to provide children with disabilities with the same legal protection afforded to children without disabilities who are no longer cared for by their parents. We consider that the CYP&F Act 1989 can and should be seen as a positive pathway with built in protection for children and young people with disabilities and their non-disabled peers under the same legal obligations. The separate provisions under Sections 140 – 149 CYP&F Act can be removed without any further changes to legislation.

Not all families have the same reasons to place their child with a disability in an out-of-home placement. Often it is the interplay and gradual accumulation of child /family related dynamics that effect placement decisions. This involves assessing the child's needs, their parents' capacity to care for them and the environment they live in. Some factors that influence out-of-home placement for parents with children with disabilities include:

- the complexity of the child's day to day care needs
- therapeutic needs
- behavioral issues
- work situation of the parents
- siblings care and support needs
- the pressures on family relationships (single parenting, isolation, stress and coping)
- social deprivation /disadvantage
- lack of support or resourcing
 - financial resources – income, savings, credit
 - material resources – house, car, phone, equipment
 - personal resources – skills, experience, attitudes, knowledge
 - social resources – family and community networks and supports
 - mental physical resources – health, strength, energy
 - logistical resources – time, proximity to supports and services.

The risk factors for residential out-of-home placement have not changed significantly and present in varying clusters across all families – whether a child with a disability is part of the family or not. We consider that the additional sections 141 and 142 have the effect of blurring of disability, care and/or protection and makes the determination of responsibility for the child's long term wellbeing more difficult to resolve.

Currently, for a range of different reasons, very few disabled children in out-of-home placements under sections 141 or 142 of the Children, Young Persons, and Their Families Act 1989 return home to live with their families.

Question 3

What support and changes do you think might be needed so that children and families can live together again (when this is possible and in the

child's best interest)?

Response:

Under CYP&F Act, the current extended care agreements have time restrictions, conditions and monitoring requirements. A return to the home or wider family whanau is the expected outcome.

When a child or young person returns to the family home, comprehensive transitional planning is key to the successful reintegration of the child to his her family:

- Determination that the parents and family are ready to resume the day to day care needs of the child and understand the readjustments they will need to undertake
- Parents continue to be fully engaged and maintain their presence in their child's life during the out-of-home placement
- Teaching and supporting parents and the wider family network how to maintain care needs, behavioral support and consistency in the disabled child's daily structures and routines
- Continued social work involvement from the time the placement is made, to plan for the return home
- Sharing the care arrangements either formally with contracted providers or informally with other family members
- Consideration for allied health and disability supports such as equipment, home modifications, schooling and therapy services in addition to family training
- Supporting families financially to move, or funding building work to provide adequate living conditions for the whole family to facilitate the return home

Some disabled children who are in out-of-home placements live with foster families. Others live in residential homes for disabled children.

Question 4

In your view, what makes a good out-of-home placement?

Response:

The most important consideration in establishing a stable out-of-home placement is the quality of consistent support staff with appropriate developmental training, and a compatible fit with the child's needs. Accommodation and support from paid staff can provide day to day care but it is the added dimension that gives children a home which is the key. Coordinated planning and approach for entry into an out-of-home placement is critical including:

- The child and family are supported and fully informed during the entry processes with open lines of communication.
- Close association and relationships with the family / whanau and networks

(including NASC, Education, MSD, Behavior Support Services, Work and Income and CYFs) is maintained while the child is in an out of home placement. Transparency across all sectors in regards to the success or failure of a placement is imperative.

- The number of children or young people in the placement is limited to no more than four.
- Local accommodation and schooling options considered for the child's connections with their community to continue with little disruption to routines in those settings.
- Placement environment is appropriate to the child's needs.
- Comprehensive hand-over of crucial information and personal belongings that will assist the child to settle.
- Acknowledgement of the child's emotional wellbeing following placement outside of the family including consideration of counselling if it is identified that it is needed.
- Regular reviews (including joint reviews if needed) of the child's progress in the placement.
- Trained staff with developmental and supportive behavior plans.
- Therapeutic interventions and monitoring of medications.
- Future planning for the child and young person to have security and direction as they grow and develop.

Children have a right to an ongoing relationship with their families. However, it can be difficult for disabled children and their families to keep or rebuild strong relationships when they go into an out-of-home placement. Some disabled children and families lose touch.

Question 5

What would you suggest are the best ways of supporting disabled children and families to maintain strong relationships during an out-of-home placement?

Response:

Maintaining the focus on the child, young person and their family even when their families can no longer provide their day to day care. This includes maintaining and reinforcing the child's or young person's connection with their family.

- Families look for somewhere for their child to live close to their family home and with flexible opportunities so they could remain involved.
- Residential schools for children with disabilities These were seen as "being like boarding school" and so considered to be a more socially and psychologically appropriate alternative.

- Residential schools also offered the opportunity to have their children home at weekends and for holidays.
- Engagement with support services and networks.

It is important to ensure the right safeguards are in place to protect the interests and rights of disabled children, and that they are treated in a way that does not disadvantage them because of their disability.

Question 6

What else might be needed to ensure disabled children can have their say and participate in decision-making about living away from their families?

Response:

The existing CYP&F Act supports the pathway for out-of-home placement. There are protections already built into the provisions under the CYP&F Act including:

- Section 10 - duty of court and counsel to explain proceedings
- Section 11 – duty of court and counsel to encourage and assist child or young person to participate in proceedings
- Section 163 - a lay advocate or court selected lawyer is appointed to ensure that the child's interests are protected.

Question 7

What could be done to ensure the rights of children who are (or are likely to be) in out-of-home placements are recognized, respected and protected?

Response:

The principles of the United Nations Convention on the Rights of the Child, The New Zealand Health and Disability Commissioner Act, and the Code of Rights for Consumers of Health and Disability Services all support the notion that the rights of children are recognised and that they are not diminished by the presence of a disability. We consider therefore that the separate provisions for disabled children under the current legislative framework are not required and need to be removed.

The removal of disability specific provisions from the CYP&F Act 1989 we think would normalise the pathway for the Department of Child Youth and Family Services to support families /whanau to achieve wellbeing for their children and young people. This reinforces CYF's role as the agency, through the state, when necessary which assumes the role of parents and includes the following:

- An existing policy framework to support children and their families
- Using section 15 referral to CYF as the entry point for children and young people

with disabilities who would have previously entered the system via a section 145 referral

- Undertaking a formal care and protection investigation
- Using the process under section 20 for all FGC's and discontinue the use of S145 FGC
- Continue to use S139 placements for responding to crises involving children and young people with disabilities, ie as for any other child in this situation
- The care provisions of section 139 can be used to strengthen the capacity of the family to resume full-time or regular care of the child, before an out of home placement is considered
- When an out of home placement is considered the child has an independent voice, counsel for the child appointed so that the child's interests and welfare are recognised and represented
- When an out of home placement is considered placement with members of his or her own family, whanau or another family and the child's involvement in education and other aspects of their lives in their existing community will be disrupted as little as possible
- Consideration for families to contribute financially to the cost of day-to-day care of their child (food, shelter, and clothing)
- Any state contribution to day to day costs such as food shelter and clothing be provided by the work and income benefit support system
- Ministry of Health DSS contribute disability support services to a child with disabilities

Most children and young people with disabilities and chronic health conditions live and thrive at home with their families. All families face minor to major stressors and while some families grow, develop and adapt through the peaks and troughs of raising a family - not all families cope. The ability of family members differs from person to person in acceptance and living alongside disability and its impacts on their lives.

For some, the decision for out-of-home placement is not strongly influenced by the problems of the child but more by the parents' lack of parental competence and strengths. Some parents see their child with a disability as a burden with deficits and regard them as being "too difficult" to care for in a family. While others simply do not show compassion or care for their child and are not committed to attending to the child's everyday needs. Yet again there are families that grow and prosper in the midst of raising a disabled child.

Abuse and violence of vulnerable disabled children does not always present as visible physical or sexual assault, but may also include passive indirect neglect, abandonment, lack of support in everyday routines and tasks, medical, therapeutic interventions, social isolation, withdrawal of opportunities to grow and develop, withdrawal of love and financial all of which needs to be recognized as part of harming the child's developmental opportunities and wellbeing.

Question 8

What changes could be made to the law to ensure that disabled children's rights are protected in the same way as other children who are in out-of-home care?

Response:

The focus on children and young people, rather than disability is sufficient reason to repeal and remove sections 140 – 149 agreements for extended care of severely disabled children, in the Child, Young Persons and Their Families Act 1989.

The CYP&F Act 1989, the Care of Children Act, The Crimes Act for Vulnerable people along with the principles of the United Nations Convention on the Rights of the Child, The New Zealand Health and Disability Commissioner Act and Code of Rights for Consumers of Health and Disability Services ensures that children are cared for and protected from harm, even when their families can no longer provide their day to day support needs. It is core business for Child, Youth and Family Services to support families /whanau to achieve wellbeing for their children and young people. Children and young people with disabilities are children first, their disabilities do not define them.

There is currently no provision made in law for when a disabled young person in an out-of-home placement turns 17. Parents remain the young person's legal guardian until they reach 18 years and make decisions about where the disabled young person will live.

Question 9

What changes might be needed to support disabled young people to successfully transition to other living arrangements, such as living in the community with other people or by themselves with support if needed?

Response:

Key to establishing a successful transition to other living arrangements as the child, young person's needs and focus change is a focus on the individual and accessing whole of life services with an appropriate compatible fit with the young person's needs. Consideration include:

- Coordinated planning and approach for entry to other living arrangements
- The child, young person and family are supported and fully informed during the transition processes with open lines of communication
- Local options are considered for the young person to maintain their connections with their family networks and community
- Placement environment is appropriate to the young person's needs

- Comprehensive hand-over of information and personal belongings that will assist the young person to transition and settle
- Acknowledgement of the young person's emotional wellbeing following transition to other living arrangements including consideration of counselling if it is identified that it is needed
- Regular progress reviews
- Trained staff and supportive behavior plans
- Therapeutic interventions and monitoring of medications
- Future planning for the young person to have surety and direction as they grow and develop
- Close association and relationships with the family /whanau and networks maintained

Other comments

Do you have any other comments or suggestions that you would like to make, or is there anything else you would like to tell us?

Response:

Submitter details

Contact details:

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Organisation details:

Organisation name: New Zealand Needs Assessment Service Coordination Association (NASCA)

Role in organisation: Chairperson

What does your organisation do (e.g. provide services, represents the interests of disabled people etc.)?

NASCA is a representative body of all NASCs involved in the support (needs assessment and service coordination) of children with disabilities. NASCs are contracted by the Ministry of Health Disability Support Services.

Other information

What is your particular interest in the disabled children: voluntary out-of-home placement review?

This legislation and the provisions for out of home placements is an important part of enabling and defining the way we work to support families of children with disabilities.

Have you or your family ever been affected in some way by section 141 or 142 of the Children, Young Persons, and Their Families Act 1989?

No

If yes, please tell us how:

Can we contact you if we want to discuss the information you've provided?

Yes by email

Would you like to be added to the mailing list to receive copies of the regular newsletter for the review? **Yes / No**

If yes, please make sure we have your email address.

Personal information and Official Information Act requests

Would you like your name and contact details to be blacked out if your submission is publicly released because it is requested under the Official Information Act 1982?

Yes / **No**

Is there any other information in your submission that you would prefer not to be released under the Official Information Act?

Yes / **No**

If yes, please clearly state what information you'd prefer not to be released and the reasons below:

Thank you for completing this submission form

Please send it to us by email to: dcp@msd.govt.nz

Alternatively, you can post it to:

The Disabled Children Project
Ministry of Social Development
PO Box 1556
Wellington 6140

You can also have input in the review by requesting to join the closed Facebook group or attending one of the regional forums – details are on the project website: www.msd.govt.nz/disabled-children-project