



**Submission on the Children, Young Persons and Their
Families (Oranga Tamariki) Legislation Bill**

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Contents

1.	Key points and recommendations	3
2.	About IHC	8
3.	Introduction	10
4.	Making children and young people with intellectual disability visible within Oranga Tamariki – what will the changes mean for them?	12
5.	Reflecting the rights of intellectually disabled children and young people in the Bill	15
5.1	The right to be safe	15
5.2	Rights to family	16
5.3	Identity	16
5.4	Privacy	17
6.	Need for an overarching strategy or plan to avoid categorizing and stigmatising children and young people	18
7.	Children and young people with intellectual disability and vulnerability	20
7.1	Risk of diagnostic overshadowing	20
7.2	Risk of over “vulnerabilising”	20
7.3	Importance of social work practice that takes disability into account ...	21
8.	What do the principles in the Bill mean for intellectually disabled children, young people and their families?	22
8.1	Participation	22
8.2	Disability Principle	24
8.3	The child’s right to be with family	24
8.4	Consent	27
9.	The importance of timely access to quality services	29
10.	Out of family care	31
11.	Transition	33
12.	Youth Justice	34
12.1	Moves to begin bringing 17 year olds within the youth justice system .	34
12.2	Appointment of youth advocate	34
12.3	Referral to care, protection and wellbeing services	35
12.4	Custody	35
13.	Information sharing	36
Appendices		
	Appendix One	38
	Appendix Two	41
	Appendix Three	42

1. Key points and recommendations

There are several specific aspects of this Bill that IHC strongly supports:

- the principle that decision-making respects the rights of children and young people with specific reference to United Nations Convention on the Rights of the Child (UNCROC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD);
- the repeal of section 141 and 142 so that disabled children and young people in State care are subject to the same protections and safeguards as all children and young people;
- the enhanced participation principle, particularly the provision of assistance; and
- the extension of the youth justice jurisdiction to include 17 year olds, the application of the best interests principle to the youth justice part of the Act, and the ability to consider to issues of wellbeing in responses to offending.

However, the number of details about how the proposed changes will operate still to be worked out coupled with the lack of certainty around how new, undefined terminology will be interpreted and applied, raises concerns about the clarity and cohesiveness of the legislation and, more generally, the new operating model itself, particularly in the transition phase, and how this will impact on disabled children and young people. Although the Bill may have good intent IHC is concerned that there is grave potential for unintended consequences and subsequent disadvantage for disabled children and young people.

The focus on vulnerability under this legislative framework remains extremely problematic. It is not clear:

- which individual disabled children and young people will be subject to State intervention under the Bill and what the nature or ramifications of that intervention might be; and
- whether disabled children and young people (or the children of parents who have intellectual disability) as a population class will be subject to more State intervention than non-disabled children and young people.

This submission makes the following key points:

- i. The wellbeing and outcomes for disabled children, young people and their families depends on timely access to flexible, integrated, timely and quality services and supports, including access to universal services. Access to inclusive education is a particularly critical issue for disabled children and young people.
- ii. High levels of awareness and understanding about the rights, wellbeing and interests of disabled children and young people and the capacity to promote, protect and fulfil their rights, will be required across all service areas of Oranga Tamariki.
- iii. The Bill, and the policies and practices under it, must strike the right balance between two risks for intellectually disabled children and young people:
 - diagnostic over-shadowing, whereby abuse and neglect are not recognized, or the threshold for intervening to keep a child safe is higher, because of the child or young person's disability
 - over-“vulnerabilising”, whereby children and young people are labelled vulnerable due to their disability only and therefore and automatically subject to intervention under the Act with potential consequences for both their family relations and privacy.
- iv. The diminished role of family/whānau, hapū and iwi in the Bill is extremely concerning, especially in light of the emphasis on early intervention to ensure children are in a “safe, stable and loving” home. It raises the spectre of children and young people being removed from, or not living with, their families for reasons other than safety.
- v. Repeal of sections 141 and 142 is welcome as it means disabled children and young people will have the same legal protections as non-disabled children and young people when they move into out of home care.
- vi. National Care Standards will be critical to how the care system recognises and accommodates intellectually disabled children and young people. Their development should be based on a transparent, consultative process and they should be subject to independent and regular review.
- vii. The transition provisions in the Bill need to ensure that young people with intellectual disability are provided with the assistance, accommodations and support they need to live independently, be included and participate in their community.
- viii. Moves to include 17 year olds in the youth justice system, while welcome, do not go far enough and are a missed opportunity to enhance the justice system's ability to recognise and accommodate children and young people with an intellectually disability and neurodisabilities.

- ix. The potential for discrimination and breach of privacy under the proposed information-sharing provisions is extremely concerning. Of particular concern is the potential for
- families to be discouraged from seeking support;
 - trust relationships to be undermined, which may result in reluctance to disclose issues of concern and seek assistance; and
 - the potential breach of the privacy rights of disabled children, young people and their families.

Our recommendations are that:

- (a) Government develop and adopt a comprehensive strategy for the implementation of UNCROC that encompasses all children and all their rights, including disabled children and their rights, to ensure a comprehensive and cohesive approach to policy affecting children and young people, including those with disabilities.
- (b) The name of the Ministry of Vulnerable Children/Oranga Tamariki be changed to remove the word “Vulnerable” to avoid the categorisation of children, in law and policy, which may lead to stigmatization and discrimination.
- (c) The purpose section of the Bill be strengthened by ensuring that children, young people and their families have timely access to flexible, integrated, quality services that advance their wellbeing and long term outcomes.
- (d) Systematic efforts are made to ensure those working across all of Oranga Tamariki’s service areas are equipped to recognise and respond appropriately to intellectual disability in order to:
- guard against diagnostic over-shadowing;
 - protect disabled children and young people from undue State intervention in their lives, and the lives of their family; and
 - promote the rights, well being and interests of disabled children and young people to family and State support.
- (e) The detailed design on the new model clarify and make transparent the interface between family support services provided under Oranga Tamariki and disability support services provided by other government departments and agencies.
- (f) Section 5A be amended to affirm, more broadly, children’s participation rights by inserting a new subsection (1) along the following lines:
- In all matters affecting them and related to the administration and application of this Act children and young people have the right to be supported to express their views freely and have those views taken into account.*
- (g) The word “encouraged” in section 5A(1) be replaced with the word “supported”.

- (h) Accommodations are made, and training, guidelines and codes of practice developed to ensure disabled children and young people can participate meaningfully and equitably within all service areas of Oranga Tamariki, particularly in relation to decision-making that affects them directly.
- (i) Where necessary, the child or young person have access to an independent advocate to help communicate their views and preferences and ensure these are taken into account.
- (j) Section 144 of the CYFA be amended to require all children to give their consent to agreements for extended care, regardless of disability, either themselves or through an independent advocate.
- (k) The words “any disability” be inserted within the parenthesis in principle 5(ix).
- (l) Principle 5(x) be re-worded along the following lines:

Disabled children and young people receive support, reasonable accommodation and assistance to enjoy their rights on an equal basis with non-disabled children and young people.
- (m) The principles in the Bill reflect the importance of family, whānau, hapū and iwi to children and young people and their status within the legislation is not diminished from that in the existing objects of the CYPF Act.
- (n) The existing principle 5(a) be reinstated in the Bill. This could be done in the following way
 - Section 5(b)(v) reads (emphasis added):

“(v) wherever possible, a child’s or young person’s family, whānau, hapu, iwi, and family group should participate in the making of decisions affecting that child or young person; and”
 - A new clause 5(c)(i) is inserted that reads:

“(i) wherever possible, consideration is given to the views of the child’s or young person’s family, whānau, hapu, iwi, and family group.”
- (o) The principles of mana tamaiti (tamariki), whakapapa, and whanaungatanga apply universally.
- (p) Proposed new section 13(2)(b) be deleted from the Bill and possibly replaced with a principle that as far as possible interventions should be developed jointly and by agreement with all involved, taking into account the views of the child or young person and ensuring independent advocacy for the child or young person especially if they have communication difficulties.

- (q) Section 144 of the CYFA be amended to require all children to give their consent to agreements for extended care, regardless of disability, either themselves or through an independent advocate.
- (r) National Care Standards be required to include specific reference to the rights and needs of disabled children and young people, including their right to accommodations and supports that ensure they enjoy the same protections as non-disabled children and young people in care.
- (s) The Bill make it a duty of the Chief Executive to co-ordinate with other government funded disability and learning support services designed to improve the wellbeing of and outcomes for disabled children and young people.
- (t) A principle be included in section 386AAC (clause 115) that disabled young people be provided with assistance, reasonable accommodation and support to live independently, be included and participate in their community.
- (u) Those working in the transition service area be trained in, and able to provide, appropriate assistance, support and guidance for those with intellectual disability transitioning from Oranga Tamariki care.
- (v) The opportunity be taken to repeal section 238(1)(e) of the Children, Young Persons and their Families Act 1989 (CYPF Act) which allows young people to be detained in Police cells.
- (w) That the existing section 66 regarding information sharing be carried over with the addition of:
 - immunity for disclosures made in good faith; and
 - an amended section 66C (clause 38) setting out and clarifying what information may be shared and on what basis.

IHC requests the opportunity to present an oral submission on the bill.

2. About IHC

IHC¹ advocates for the rights, inclusion and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community. Underpinning our work is the principle that intellectually disabled children and young people are part of the community of all children and young people – they are entitled to full enjoyment of their human rights and fundamental freedoms on an equal basis with other children and young people².

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare and inclusion of all people with an intellectual disability throughout their lives. We support people with intellectual disability to lead satisfying lives and have a genuine place in the community as citizens. We believe that the foundations for inclusion of people with intellectual disability in society are built on the integrated support offered to families of children with intellectual disability.

Through our charitable arm IHC raises awareness and advocates for the rights of over 50,000 people with intellectual disability at both a national and an international level. This includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library.

We support around 6,000 people with intellectual disability in IDEA services (IHC's service arm) that include residential care, supported living, home support, employment and community participation and inclusion, support for families, specialist services, autism spectrum disorder (ASD) services, and through Accessible Properties (a subsidiary company of IHC) are New Zealand's largest non-government social housing provider.

IDEA Services has contracts with Child, Youth and Family and the Ministry of Health and currently provide services for approximately 2,000 children and young people. These services include foster care, home and community support, respite care, holiday programmes, parent training (ASD Plus and Growing up with Autism) and an ASD Communication and Behaviour Service.

This submission uses a child's rights approach with particular reference to the UNCROC and the UNCRPD (see Appendix 1).

Two questions form the basis of our submission:

¹ More information about IHC is contained in Appendix 1.

² United Nations Convention on the Rights of Persons with Disabilities and United Nations Convention on the Rights of the Child

1. How will the changes proposed in this Bill impact on intellectually disabled children and young people, and their families – is there any scope for discrimination?
2. To what extent will the Bill ensure the new Oranga Tamariki operating model meets the rights needs and interests of disabled children and young people?

IHC's advocacy and service provision arms connect regularly with families in communities. This submission draws on the experiences of children and young people with intellectual disability and their families shared with us, and on what we know from research. IHC's submission reflects our long held position that children and young people with intellectual disabilities belong in their families and good outcomes for them occur when they have access to universal and specialist support which is timely, flexible, integrated across government and is of high quality.

3. Introduction

“Some stories enhance life, others degrade it so we must be careful about the stories we tell and about the ways we define ourselves and other people”
Burton Blatt (1987)³

IHC welcomes the opportunity to submit on the Children, Young Persons and Their Families (Oranga Tamariki) Legislation Bill (the Bill).

The potential impact of this Bill on the lives of disabled children, young people and their families should not be underestimated. This Bill will contribute to shaping expectations and messages about how intellectually disabled children and young people can and should be able to live their lives; how they come to know who they are; their relationships with their families; how welcoming and inclusive the communities they live in are; how the ethical, policy, practice and funding decisions that affect them are made and their ability to have a say in those decisions; the quality of services and supports they receive; and how well the safeguards put in place for them actually work.⁴

There are several aspects of this Bill that IHC strongly supports:

- the principle that decision-making respects the rights of children and young people with specific reference to UNCROC and UNCRPD;
- the repeal of section 141 and 142 so that disabled children and young people in State care are subject to the same protections and safeguards as all children and young people;
- the enhanced participation principle, particularly the provision of assistance; and
- the extension of the youth justice jurisdiction to include 17 year olds, the application of the best interests principle to the youth justice part of the Act, and the ability to consider the issues of wellbeing in responses to offending.

However, due to the amount of detailed design work still to be completed it is unclear how the new model will operate in practice and therefore it is difficult if not impossible to assess or comment meaningfully on what the proposed changes will mean for intellectually disabled children, young people and their families.

Nevertheless the overall tenor of the Bill is problematic. While IHC supports increased attention to children and young people’s participation in decision-making under the Act we question whether this necessitates a diminished role

³ Burton Blatt (1987) cited in John O’Brien and Beth Mount (1991), *Telling new stories: The search for capacity among people with severe handicaps*. In L.H. Meyer, C.A. Peck and L. Brown (Eds.) *Critical Issues in the Lives of People with Severe Disabilities*. P.89.

⁴ IHC (2015). Valued, good and ordinary lives.
http://www.ihc.org.nz/sites/default/files/documents/IHC%20Advocacy_Valued%20good%20and%20ordinary%20lives_0.pdf

for families, whānau, hapū and iwi. IHC is concerned with the signaled shift from “working with” to “doing to” children, young people and their families and that risks undermining rather than enhancing their wellbeing. Child-centred does not mean excluding families

Although data is limited, children and young people with intellectual disability are likely to be over-represented in both the care and protection and youth justice systems. Also their experience of the changes regarding care, transition from care and information sharing, and the implications of those changes for them, may differ from their non-disabled peers. For example, they may require additional advocacy and supports to ensure their rights and needs are met.

Central to the wellbeing of intellectually disabled children, young people and their families is timely access to integrated, flexible and high quality universal and specialist supports and services. The recent case of Ruby Knox, who was murdered by her mother, highlights how failure to provide supports tailored to a child or young person and their family’s needs can have the most tragic of outcomes.⁵

While it is not clear yet what supports could and should have been available from childhood to adulthood for Ruby and her mother, or what barriers there may have been to accessing those services, the serious and contemporary issues related to Ruby’s life and death are pertinent and relevant to this Bill.

In its current form the Bill lacks clarity as to whether children and young people like Ruby will come within the Oranga Tamariki framework or even whether any consideration has been given to whether they should given the clear links between adequate support and vulnerability for disabled children and their families.

In summary, IHC is concerned about the Bill’s potential to create a stigmatising and disempowering framework for State intervention in the lives of those children, young people and their families deemed vulnerable while simultaneously leaving others without access to the services and supports that are essential to their wellbeing.

IHC submits that the current legislative regime is fundamentally sound and well able, with some adjustments and proper resourcing, to deliver a balanced, truly child-centred care, protection and youth justice system.

⁵ <http://www.stuff.co.nz/national/crime/89179331/independent-review-of-donella-and-ruby-knoxs-treatment-set-for-may>

4. Making children and young people with intellectual disability visible within Oranga Tamariki – what will the changes mean for them?

The number of uncertainties about how Oranga Tamariki will work in practice and the lack of robust data about intellectually disabled children, young people and their families⁶ makes it difficult to estimate how many, and which, children and young people will be affected by the changes in the Bill.

A disproportionate number of children with disability may be included within the expanded Oranga Tamariki framework because without adequate supports they are more likely to experience disadvantages that can undermine their long term outcomes, render them vulnerable to abuse and neglect, and bring them within the youth justice system.

Disabled children are three times more likely than non-disabled children to be abused or neglected and these rates are even higher for children with communication impairments, behaviour difficulties and intellectual disability and sensory disabilities.⁷

Although data is very limited indications are that a disproportionate number of those within the existing care and protection and youth justice systems are likely to have disabilities. The Ministry of Health has reported that 15% of those aged under 16 and 19% of those aged under 28 who receive Disability Support Services have had a Child Youth and Family finding of abuse and neglect⁸. Although not directly comparable, in 2016 13,598⁹ distinct children and young people had a substantiated abuse or neglect finding. That is approximately 1.2% of the 1.1 million children and young people in New Zealand.

In relation to out-of-home care placements, a snapshot study on 31 August 2014 found that there were, at that time, 48 disabled children in care under section 141 of the CYPF Act. They were aged between 9 and just over 17 years of age. The average age was 14 and-a-half years. About 65% went into out-of-home placement at the age of 12 years or above, with the youngest being just over one year of age. Approximately 90% were male, two-thirds were of European descent and about 23% identified as Māori. Many had more than one disability. Two of the most common were autism spectrum disorder (about 40%) and intellectual and learning disabilities (43 %).¹⁰

Young people with intellectual disabilities are also likely to be over-represented in the youth justice system. Once again there is a lack of data but based on research in the United Kingdom, and a small number of New Zealand studies,

⁶ Lack of robust data about disabled children, young people and their families is a perennial issue. See ACYA *Counting what matters – Valuing and making visible the lives of children with disabilities. Supplementary information for the United Nations Committee on the Rights of the Child.* August 2016.

⁷ IHC, *Making citizenship and rights real in the lives of people with intellectual disabilities*, page 6. Available at <http://www.ihc.org.nz/making-citizenship-and-rights-real-lives-people-intellectual-disabilities>

⁸ Ministry of Health (2015) What do we know about people receiving MoH Disability Support Services. Retrieved from <http://www.odi.govt.nz/whats-happening/ministers-forum-follow-up-information/>

⁹ Child, Youth and Family, Key Statistics. Retrieved from: <http://www.cyf.govt.nz/about-us/key-statistics/findings.html>

¹⁰ *Disabled Children: voluntary out-of-home placement review. Public Consultation Document.* March 2015. Ministry of Social Development.

the prevalence of neurodevelopmental disorders in the youth justice system is said to be 'sky high.'¹¹ The United Kingdom study found that 23-32% of young people in custody had generalised learning (intellectual) disability, compared with 2-4% of the general population¹².

Especially when their disability has not been recognised or they have not received effective support, disabled young people may have characteristics or traits, such as hyperactivity or low impulse control, that lead to offending.¹³

Once young people are in the justice system their disability may make it difficult for them to understand the process and or appreciate any potential impact on their longer term wellbeing. The justice system can be an uncomfortable and frightening experience for anybody; this is compounded for those who have an intellectual disability.¹⁴ The ability of the youth justice system to respond to intellectually disabled young people depends on those involved communicating effectively and taking the time to listen to the young person's experiences and story, in order to understand how their disability may have contributed to their offending, and ensure a fair response. This includes having their intellectual disability recognized and ensuring that appropriate assessment is undertaken. As has been mentioned some young people who come into the justice system have not had their intellectual disability diagnosed.

Yet there appears to have been only limited analysis of how the proposed changes will impact on intellectually disabled children and young people and very little attention given to how processes under the Act will be designed to accommodate them and respond fairly and appropriately if they offend.

It is acknowledged that many of the details about how the proposed changes will operate are still to be worked out. This, coupled with the lack of certainty around how new, undefined terminology will be interpreted and applied raises concerns about the clarity and cohesiveness of the legislation and, more generally, the new operating model itself, particularly in the transition phase, and how this will impact disabled children and young people.

Further, many factors outside this Bill will influence the capacity of Oranga Tamariki to enhance the wellbeing of disabled children and young people and be critical to the new operating model's effectiveness. For example:

- Legislation and policy regarding standard of living, education (especially inclusive education), health, housing, drug and alcohol abuse, domestic violence¹⁵.

¹¹ *Neurodisability in the Youth Justice System in New Zealand: How Vulnerability Intersects with Justice*. Report prepared by Dr Nessa Lynch, Faculty of Law, Victoria University of Wellington, in conjunction with Dyslexia foundation of New Zealand (DFNZ), summarising the contributions of participants at the 2016 Neurodisabilities Forum, hosted by DFNZ in Wellington, 12 May 2016. Retrieved from: <http://neurodisabilitiesforum.org.nz/>

¹² Children's Commissioner (England) *Nobody made the connection: the prevalence of neurodisability in young people who offend*. October 2012. Page 9.

¹³ Above n12, page 10.

¹⁴ Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates, Mark Henaghan *Developing a more responsive legal system for people with intellectual disability in New Zealand*. (2014) Donald Beasley Institute. Retrieved from <http://www.donaldbeasley.org.nz/resources/publications/law/>

¹⁵ For an outline of the predisposing, perpetuating and precipitating factors involved in child maltreatment see *Preventing physical and psychological maltreatment of children in families: Review of research for campaign for action on family violence*. Centre for Social Research and Development. March 2008. Available

- The level of human, technical and financial resourcing applied to Oranga Tamariki.
- The cohesiveness, inclusivity and quality of the universal service provision on which Oranga Tamariki rests.

IHC notes, and endorses, Treasury advice:

“In particular, the problem definition does not sufficiently identify the root causes of the failure of system actors to take a child-centred approach. The RIS identifies the influence legislation can have on expectations and practice, but does not adequately demonstrate that current legislation is an impediment to system actors taking a child-centred approach and therefore does not establish that legislative change is a necessary response.

It will therefore be important, in the detailed design of the new arrangements, to identify and address factors other than legislative requirements that affect agency and practitioner decision making.”¹⁶

As the Social Service Providers Aotearoa have noted in their submission, it cannot be said with certainty whether the problems the Bill aims to address lie with the current Act *per se* or how the Act has been put into practice.

For disabled children, young people and their families a crucial factor affecting the new model’s effectiveness will be capacity including levels of awareness and understanding about disabled children and young people and their rights.

In summary, while IHC supports the stated intent of the Bill to create a child-centred care and protection system and a balanced youth justice system, we question the extent to which the changes proposed are necessary to achieve that aim and urge careful consideration to ensure the Bill will contribute to a non-disabling and inclusive child protection, care and youth justice systems that supports, and does not create barriers to, disabled children and young people leading valued, good and ordinary lives.

at <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/literature-reviews/preventing-maltreatment/preventing-maltreatment.pdf>

¹⁶ Departmental disclosure statement for the Children, Young Persons and Their Families (Oranga Tamariki) Legislation Bill. Page 17. Retrieved from <http://disclosure.legislation.govt.nz/bill/government/2016/224/>

5. Reflecting the rights of intellectually disabled children and young people in the Bill

IHC strongly supports the specific inclusion of UNCROC and the UNCRPD within the Bill (proposed subsection 5(a)(i), clause 8).

In developing this submission we have considered the extent to which the Bill advances or compromises the rights of intellectually disabled children and young people under either UNCROC or the UNCRPD, specifically:

- What the likely impact on disabled children and young people is, especially given the scope for more children and young people to be included within the care, protection and wellbeing systems under the Bill.
- Whether there is any potential discrimination (direct or indirect) against disabled children and young people under the Bill.
- Whether the Bill creates an inclusive institutional framework for the child protection, youth justice and care systems.

An outline of disabled children and young people's rights in relation to the Bill is attached as Appendix 2.

Under UNCROC, children have protection, participation and provision rights. The Convention must be considered as a whole; the rights and principles it contains are interdependent and indivisible. A child rights approach or framework involves taking all children's rights into account, and weighing them up against each other, to identify in any given situation what course of action is in the best interests of the child.

On balance, we are concerned about the Bill's potential to create an unduly complex system of child care, protection and wellbeing that undermines rather than upholds the rights of disabled children and young people, especially their rights to:

- be safe;
- know, be guided and cared for by their families and for their families to be supported in their caregiving role;
- identity; and
- privacy.

5.1 The right to be safe

The Bill establishes a higher threshold for defining a child or young person as being in need of care and protection. Currently a child or young person is in need of care and protection if, amongst other things, they are at risk of harm (section 14 CYPFA). However, under the proposed new section 14 there has to be risk of serious harm for a child or young person to be defined as in need of care or protection.

The higher threshold, compounded by diagnostic overshadowing, may mean that disabled children and young people are not identified as being at risk of harm when they should be, compromising their safety. We recommend that the word "serious" be removed from proposed new section 14(1).

At the same time as the threshold for reporting safety concerns has been raised, we note that the proposed new section 15 allows concerns about the wellbeing of a child or young person to be reported to a constable or social worker and that, under proposed new section 17(2A), the Chief Executive may undertake further assessment, provide services or refer the child, young person, their family or usual caregivers to services. The Chief Executive may also make a family group conference available without a finding that a child is in need of care or protection. IHC supports these amendments.

However, given the wider grounds for reporting concerns about children and young people it seems likely that notifications will increase, putting pressure on the ability of Oranga Tamariki to respond well to safety concerns and increasing the risk that children and young people will be harmed.

Many commentators, over many years, have raised concerns about shortcomings in the levels of resourcing and support for the operation of the Children, Young Persons and their Families Act 1989 (CYFA) limiting the cases Child, Youth and Family (CYF) becomes involved in to those involving the most imminent threats of harm. We are concerned that the changes proposed will do nothing to address, and may well exacerbate, existing concerns about the capacity of Oranga Tamariki to respond well to care and protection concerns.

5.2 Rights to family

IHC's advocacy and service provision arms connect regularly with families in communities. This submission reflects IHC's long held philosophical position that disabled children and young people belong in families and good outcomes occur for disabled children and young people when they have access to universal and specialist support which is timely, flexible and of high quality. Families report that there are barriers to accessing what they need and the stress associated with this can create situations where families reach crisis point.

IHC is extremely concerned about fundamental changes to the objects/purposes and principles of the Act, which diminish the status and role of family, whānau, hapū and iwi under the legislation and threaten children and young people's rights to know, be cared for and, when separated, maintain contact with their parents and families¹⁷.

5.3 Identity

IHC supports the explicit recognition of respect for a child or young person's identity and the inclusion of disability in proposed section 5(a)(iv).

However, coming within the Oranga Tamariki framework may in itself have implications for children and young people's identity - they will automatically be defined as vulnerable, and the safety, stability and love of their families questioned. Such a deficit based and stigmatising approach has potential to undermine the child or young person's sense of self-worth and value.

¹⁷ See UNCROC articles

For disabled children and young people the potential negative impact on their identity and sense of self may be compounded by the general lack of valuing of the lives of those with disability.

5.4 Privacy

The information sharing provisions in the Bill have significant implications for the privacy of disabled children, young people and their families. These are discussed below.

6. Need for an overarching strategy or plan to avoid categorizing and stigmatising children and young people

Contrary to the recommendations of the UN Committee on the Rights of the Child¹⁸ the proposed changes in the Bill are occurring in the absence of any coherent, overarching strategy or vision for all children and young people in New Zealand, with or without disabilities.

Last year the United Nations also recommended that New Zealand:

“Strengthen its efforts to combat the marginalization and discrimination of children with disabilities in their access to health, education, care and protection services, with particular attention to Maori children with disabilities, children with disabilities living in poverty and children with multiple disabilities, and undertake awareness-raising campaigns aimed at government officials, the public and families to combat the stigmatization of and prejudice against children with disabilities and promote a positive image of these children.”¹⁹

IHC would prefer to see disabled children and young people made visible within a comprehensive strategy for implementing all the rights of all children and young people, of which keeping them safe from abuse and neglect, responding to youth offending and ensuring they have quality care are components^{20 21}.

As well as guarding against discrimination and positioning children and young people with disabilities as children and young people first, a comprehensive plan could address the determinants of child wellbeing and societal factors that affect the ability of parents and families to care for children and keep them safe.

The World Health Organisation has noted the following as being important influences on the wellbeing of children, young people and their families and potential societal risk factors for abuse:

- the role of cultural values and economic forces in shaping the choices facing families and shaping their response to those forces;
- inequalities related to sex and income – factors present in other types of violence and likely to be related to child maltreatment as well;
- cultural norms surrounding gender roles, parent-child relationships and the privacy of the family;
- child and family policies – such as those related to parental leave, maternal employment and child care arrangements;

¹⁸ CRC/C/NZL/CO/5. 2016. Paragraph 7(a). See also paragraph 7(b) regarding the need to avoid categorizing children in law and policy.

¹⁹ CRC/C/NZL/CO/5. Committee on the Rights of the Child. Concluding observations on the fifth periodic report of New Zealand. Paragraph 30(b)

²⁰ Such an approach was recommended by the United Nations Committee on the Rights of the Child in October 2016. CRC/C/NZL/CO/5. Paragraph 7(a).

²¹ Ireland’s “Better Outcomes Brighter Futures: the national policy framework for children and young people 2014-2020” is an example of such a strategy
http://www.dcv.gov.ie/documents/cvpp_framework/BetterOutcomesBetterFutureReport.pdf

- the nature and extent of preventive health care for infants and children, as an aid in identifying case of abuse in children; and
- the strength of the social welfare system – that is the sources of support that provide a safety net for children.²²

A comprehensive plan would also help ensure a consistent approach to policies and practices affecting all children across government.

While we note that the new duties of the Chief Executive (Clause 11 of the Bill) aim to improve co-ordination of service delivery across government this is limited to those children and young people classified as vulnerable or whom have been identified as needing assistance to improve their wellbeing and long term outcomes. It is unclear to what extent this will include disabled children and young people or how this will affect their access to disability support services through the Ministries of Health and Education.

There is a risk that these changes will become another part of the complex puzzle of services, support and State intervention that disabled children, young people and their families have to navigate in order to live safe, good, ordinary lives.

Recommendation

IHC recommends, in accordance with the recommendations of the UN Committee on the Rights of the Child and in order to ensure a comprehensive and cohesive approach to policy affecting children and young people, including those with disabilities, that:

- government develop and adopt a comprehensive strategy for the implementation of UNCROC that encompasses all children and all their rights, including disabled children and their rights; and
- the name of the Ministry of Vulnerable Children/Oranga Tamariki be changed to remove the word “Vulnerable” to avoid the categorisation of children, in law and policy, which may lead to stigmatisation.

²² Krug EG et al., eds. World report on violence and health. Geneva, World Health Organization, 2002, page 69. Retrieved from: http://apps.who.int/iris/bitstream/10665/42495/1/9241545615_eng.pdf

7. Children and young people with intellectual disability and vulnerability

Throughout our submissions on various aspects of the vulnerable children's work programme over the last 7 years IHC has consistently called for greater consideration and visibility be given to disabled children and the factors that contribute to them becoming vulnerable to abuse and poor life outcomes.

However, it remains unclear which disabled children and young people will be considered vulnerable, which will not, and what the implications are for both groups. If a disabled child or young person does not come under Oranga Tamariki will there be any implications for their access to services and support, for example?

The large amount of detail about the operation of the new model that is still to be developed, coupled with the limited reference to disabled children and young people within the legislative framework, raises concerns about the balance that will be struck between overshadowing and "over-vulnerabilising", especially within care and protection work.

7.1 Risk of diagnostic overshadowing

Diagnostic overshadowing refers to the situation where the presence of disability masks other needs, such as health or safety needs, or the problem or concern is attributed to the child or young person having an intellectual disability. This results in the risk to that child or young person being overlooked or a differentiated (often higher) threshold for intervention or access to services being applied. IHC is aware of one recent case that highlights this differentiated approach, where a child with a disability was killed having been left in the family home when the non-disabled siblings had been removed by the State.

The Bill, and the policies and practices that develop under it, must guard against overshadowing so that disabled children, young people and their families able to access the same services and supports and are afforded the same levels of protection as non-disabled children and young people.

7.2 Risk of over "vulnerabilising"

Conversely, there is a risk that children and young people with disabilities, both individually and as a group, may be subject to increased and potentially unnecessary State intervention if they are regarded as "vulnerable" due to their disability.

The Bill's expanded scope for intervention to include long-term outcomes and developmental potential raises questions about how children with intellectual disability, ASD or developmental delay will be dealt with under the new model. How will positive long term outcomes for disabled children and young people be determined and who will decide? At what point and on what grounds will children and young people receiving disability support services from the Ministries of Health and Education be eligible for Oranga Tamariki support? Which disabled children will be affected - how will those that are "vulnerable"

be distinguished from “non-vulnerable”? What are the implications for disabled children and young people characterised as vulnerable, especially in terms of their rights to privacy and to know, be cared for and guided by their family?

Critically, failures to adequately recognise and respond to disability support needs may render a disabled child or young person “vulnerable” thereby subjecting them to State intervention with consequent implications for their privacy and family relations. IHC believes that there is a strong risk of discrimination within these arrangements.

7.3 Importance of social work practice that takes disability into account

IHC has seen and supports the submission of Social Service Providers Aotearoa (Inc) that the work of CYF social workers is already highly complex and the new legislation seems likely to increase that complexity. The need to assess future harm as well as the addition of new principles will require investment in workforce capability.²³

Building that capability must include raising awareness and understanding of how disability issues for children and young people should be factored into social work practice across each of Oranga Tamariki’s service areas.

Training and support for social work practice will be necessary to guard against overshadowing, ensuring disabled children receive support and services when they need them, and also to protect disabled children and young people from being subject to greater State intervention in their lives, and their families lives, than non-disabled children and young people.

Recommendation

IHC recommends that:

Systematic efforts are made to ensure those working across all of Oranga Tamariki’s service areas are equipped to recognise and respond appropriately to intellectual disability in order to ensure that in every case the appropriate balance is struck between:

- guarding against over-shadowing; and
- protecting disabled children and young people from undue State intervention in their lives, and the lives of their family.

The detailed design of the new model will need to clarify and make transparent the interface between family support services provided under Oranga Tamariki and disability support services provided by the Ministries of Health and Education.

²³ For a useful summary of the theories of childhood and their implications for social work practice see Bell, M. *Promoting Children’s Rights in Social Work and Social Care: A guide to participatory practice*. 2011. Chapter 4, *The theoretical principles that underpin participatory practice*, pages 68 -83.

8. What do the principles in the Bill mean for intellectually disabled children, young people and their families?

8.1 Participation

IHC strongly supports having a stand-alone section within the Act setting out principles of children and young people's participation. (Section 5A)

Children with disabilities have the right to express their views on all matters affecting them and to have those views be given due weight in accordance with their age and maturity, on an equal basis with other children. They must be provided with disability and age-appropriate assistance to realise this right.²⁴ This is particularly important for those children and young people who have communication difficulties or who are non-verbal and so may need the help of others to have their views heard and understood.

Disabled children and young people's participation rights, as set out in both UNCROC and the UNCRPD, involve more than expressing views on specific issues or decisions. They include access to information and opportunities in order to be able to form views, freedom of thought and expression²⁵ and generally being respected as rights holders and active participants in their own lives.

As drafted the principles of participation appear to have a focus on one-off decisions, rather than creating an on-going culture of respect for children as active participants in their own lives and as recipients of services and support. Section 5A could be strengthened by including a general principle affirming, more generally, the right of children and young people to express their views and preferences on matters that affect them.

It should also be noted that children and young people have the right to express their views "freely". Children and young people are not obliged to express their views and should not be required to do so. It is a difficult balance between providing enabling support for children and young people to have their say and them feeling under pressure to express their views. We recommend that the term "supported" be used instead of "encouraged" in 5A(1)(a).

Giving effect to the rights of intellectually disabled children and young people to participate in decision-making will depend heavily on how these participation principles are put into practice, including such things as:

- what information and experiences they have to base their views on;
- whether information is provided to them in ways that mean they understand it;
- the environment in which they are expressing their views;
- how they communicate their views or preferences, especially when they are non-verbal;
- how well the decision-maker understands the child or young person and the nature of his or her disability and the assistance and support they need to effectively participate; and

²⁴ Articles 3 and 7 UNCRPD, and Articles 12 and 23 UNCROC.

²⁵ UNCROC Article 13.

- the level and nature of assistance provided to enable the child or young person to participate, including independent advocacy.

It is well documented that people with intellectual disabilities have a tendency to acquiesce. Also, intellectually disabled children and young people may have a more limited ability to understand what decisions they are being asked to express their views on or comprehend the consequences of expressing their preference. Particularly if they have communication difficulties or are non-verbal, understanding their preferences and supporting them to express those preferences may require time and tailored assistance. There will be times when the child or young person will require an independent advocate, such as when entering an agreement for extended care.

Training, guidelines and codes of practice will be required to ensure disabled children and young people can participate meaningfully within all aspects of Oranga Tamariki, particularly decision-making that affects them directly such as decisions around out-of-family care.

Recommendation

IHC recommends that:

- Section 5A be amended to affirm, more broadly, children's participation rights by inserting a new subsection (1) that reads along the following lines:

“In all matters affecting them and related to the administration and application of this Act children and young people have the right to be supported to express their views freely and have those views taken into account.
- The word “encouraged” in section 5A(1) be replaced with the word “supported”.
- Accommodations are made, and training, guidelines and codes of practice developed to ensure disabled children and young people can participate meaningfully within all service areas of Oranga Tamariki, particularly in relation to decision-making that affects them directly.
- Where necessary, the child or young person have access to an independent advocate to help communicate their views and preferences and ensure these are taken into account.
- Section 144 of the CYFA be amended to require all children to give their consent to agreements for extended care, regardless of disability, either themselves or through an independent advocate.

8.2 Disability Principle

New Zealand's Disability Strategy 2016-2026 (the Strategy) should guide the work of government agencies on disability issues. It promotes a whole-of-life and long-term approach to social investment that impacts on disabled people²⁶ and reflects current thinking about disability.²⁷ (See Appendix 2 for further information about shifts in thinking about disability).

IHC submits that, possibly due to the implicit focus on normative outcomes for individual children and young people, the Bill reflects outdated thinking about disability and is inconsistent with what is accepted as a person centred and whole of life approach required for appropriate rights recognition and response.

The disability principle in the Bill, to be applied in exercising powers under the Act, reads: "(x) for disabled children or young persons, the impact of their disability and any disadvantage resulting from that disability is considered and any impact mitigated."

We suggest that, as drafted, this principle casts disability as an individual problem and implies differences in abilities are inadequacies. It is deficit based, in that it anticipates exclusion by requiring steps are to be taken to make sure the disabled child or young person's special needs are considered and responded to so they fit within the mainstream care protection, wellbeing and youth justice systems rather than building systems that can accommodate disabled children and young people.

It positions the child or young person as the passive recipient of help to overcome their disability and mitigate its effects rather than requiring those exercising powers under the Act to ensure the processes and environments they create and the attitudes they display accommodate the unique situation of each child, including those with disabilities.

IHC therefore recommends:

- "any disability" be inserted within the parenthesis in principle 5(ix); and
- Principle 5(x) be re-worded along the following lines:

Disabled children and young people receive support and assistance to enjoy their rights on an equal basis with non-disabled children and young people.

8.3 The child's right to be with family

Down syndrome is what he had, not who he was. His whanau and his whakapapa connect him to us²⁸.

²⁶ Office for Disability Issues, Ministry of Social Development *New Zealand Disability Strategy 2016-2026*. Retrieved from <https://www.odi.govt.nz/nz-disability-strategy/>

²⁷ Office for Disability Issues, Ministry of Social Development. <https://www.odi.govt.nz/about-disability/shifting/>

²⁸ National Health Committee (2003) *To Have and Ordinary Life*, pg 41

IHC was founded by families seeking the best for their disabled children and young people, ensuring their rights are met within the context of their family and community. Our position has remained unchanged over the nearly 70 years of our existence. We believe that disabled children belong in their family/whānau and that family/whānau should be well supported in their role with access to what is needed for a good life for them and their children.

We also believe that whānau can only thrive if they are connected to, are valued and have a sense of belonging in their own communities. We expect:

- The knowledge, culture, expertise and advocacy of families and whānau is respected and responded to.
- Child or person-centred is not seen as excluding families.
- Families are knowledgeable about support services and how to access them.
- Families do not have to be in crisis before they can get help.
- Families have flexible support that is a 'good fit' for their family and is responsive to changing situations and developmental stages.
- Parents with intellectual disability being supported to bring up their children and keep their family together.²⁹

We are therefore particularly cautious about the changes in the Bill which diminish the importance and role of family, whānau, hapu and iwi. These changes, coupled with the increased emphasis on children's participation, suggest an oppositional relationship between being child-centred and the role of families that is extremely unhelpful.

The current legislation envisages a system of notification, assessment and response working with families, whānau, hapu and iwi to promote child wellbeing. It was based on Puaoteata-tu and developed to avoid the terrible experiences of children and young people in State care in the 1970s and 1980s, many of which have recently come to light through the work of the Confidential Listening and Assistance Service³⁰.

The changes proposed in the Bill suggest a system whereby the State, through the Chief Executive, will identify those children in families who might be harmed (now or in the future) or at risk of poor long term outcomes and intervene. In light of the information sharing provisions in the Bill it seems likely that some form of predictive risk modelling will be used to inform these judgments.

This is one of the most problematic aspects of this Bill. It is a fundamental shift of focus from protecting individual children in specific circumstances from

²⁹ IHC, *Making citizenship and rights real in the lives of people with intellectual disabilities*, page 15.

Available at <http://www.ihc.org.nz/making-citizenship-and-rights-real-lives-people-intellectual-disabilities>

³⁰ Some Memories Never Fade – Final Report of the Confidential Listening and Assistance Service. Available here: <https://www.dia.govt.nz/Final-Report-of-the-Confidential-Listening-and-Assistance-Service>

abuse or neglect to identifying groups of children who may be vulnerable to future harm, including harm to their long-term outcomes.

The nature of possible interventions (or limits on those interventions) is unspecified. State intervention will be based on whether a child is in a “safe, stable and loving” home. Neither “safe”, “stable” nor “loving” are defined within the Bill. While “safe” and “stable” may be capable of some objective assessment, it is very difficult to see how “loving” could ever be.

Taken together, the diminished family, whānau, hapu and iwi role in decision-making under the Bill and the emphasis on early intervention to ensure children are in a “safe, stable and loving” home raises the prospect of children being removed from families ‘for their own good’. While there is no question that in some cases uplifting children and young people from their home will be necessary for their safety and wellbeing this is not a step that should be taken lightly. It must be based on clear legislative authority and subject to appropriate procedural safeguards.

There is a sense that families will need to prove they can provide a “safe, stable and loving home” if they are to retain care of their children and, conversely, that seeking assistance from Oranga Tamariki will amount to an admission of not being able to provide a “safe, stable and loving home” or meet the needs of a child or young person. This may undermine the willingness of families to seek help early, if they are beginning to struggle with caring for a disabled child or young person. Particularly given the breach of confidentiality principle (principle (j)) which, in conjunction with the information sharing provisions, will mean they are opening themselves up to having information about their personal and family situation widely shared.

There are many lessons to be learnt from the past regarding how we, as a nation, exercise our collective responsibilities to care for children and young people. Many children and young people have been badly hurt by systemic failures. This includes many children and young people with intellectual disabilities who were routinely institutionalised last century as well as children, young people and families who continue to suffer systemic abuse as a consequence of a lack of timely access to services and support. The utmost care must be taken with this Bill to avoid any more systemic harm.

IHC submits these changes will have a profound impact on all children’s sense of belonging. IHC submits these are a backward step and that there is insufficient evidence that they are either justified or needed.

IHC supports the reference to mana tamaiti (tamariki), whakapapa, and whanaungatanga within the Bill but submits that the application of these principles should not be restricted to Māori children and young people. We note that, as drafted, the Bill is confusing in this regard with mana tamaiti (tamariki) being defined in clause 4 as applying only to a person who is Maori, but whakapapa, and whanaungatanga applying to “a person”.

Recommendation

IHC recommends that:

- The principles in the Bill reflect the importance of family, whānau, hapū and iwi to children and young people and their status within the legislation is not diminished from that in the existing objects of the CYPF Act.
- The existing principle 5(a) be reinstated in the Bill. This could be done in the following way:

Section 5 (b)(v) reads (emphasis added):

“(v) wherever possible, a child's or young's persons family, whānau, hapu, iwi, and family group should participate in the making of decisions affecting that child or young person; and”

A new clause 5(c)(i) is inserted that reads:

“(i) wherever possible, consideration is given to the views of the child's or young person's family, whānau, hapu, iwi, and family group.”

- The principles of mana tamaiti (tamariki), whakapapa, and whanaungatanga apply universally.

8.4 Consent

There is a distinction between supporting a child or young person to express their views and consent. Getting the agreement of everyone involved to a particular course of action that is jointly developed is likely to be good practice.

However, including a legislative requirement to seek a child or young person's consent to an intervention, as proposed in new section 13(2)(b), could effectively make the child or young persons' view determinative, placing enormous responsibility on the child or young person in circumstances where they are, by definition, subject to family crisis and possibly violence. This could have negative consequences, especially for children and young people with intellectual disability:

- If a child or young person consents to an intervention but other members of their family do not, relationships may be undermined rather than strengthened, especially if that intervention involves the child or young person effectively choosing to live with someone other than their current caregiver.
- A child or young person may feel under pressure to consent in order to “do the right thing” by either the social worker managing the intervention or parents or family members, or to avoid upsetting anyone.
- If the child or young person does not consent, or objects to an intervention, it could impact on a social worker's assessment of risk to safety.

There can be a tendency to overlook the views of severely disabled children and young people or those with communication difficulties because it is seen

as too hard to elicit their views or preferences. As already discussed, independent advocacy will be necessary in these situations, especially where consent is required (see our comments below on section 140 agreements).

Recommendation

IHC recommends that:

- The proposed new section 13(2)(b) be deleted from the Bill and possibly replaced with a principle that as far as possible interventions should be developed jointly and by agreement with all involved, taking into account the views of the child or young person and ensuring independent advocacy for the child or young person especially if they have communication difficulties.

9. The importance of timely access to quality services

A recent case from the December/January 2016/17 Children's Action Plan newsletter highlights what it means for children to only get the services they are entitled to once they are identified as vulnerable. Although presented as a success story the case can be interpreted, from a child rights point of view, as a damning indictment of the systemic failings undermining child wellbeing.

Of concern too is the way the story is told. It is acknowledged that this is just one article from the Children's Action Plan newsletter but the language used illustrates the kind of stigmatising and blaming approach to children and their families that could so easily develop under the new model. An analysis of the story is in Appendix 3.

Arguably, systemic failures made the boy in the story "vulnerable". While the article identifies some of the challenges disabled children, young people and their families face these are located in the individuals involved. It is very light on identifying the systemic issues involved.

The response once the boy is being dealt with by the Vulnerable Children's team is good practice and demonstrates the difference access to co-ordinated services and supports can make.

It begs the question as to why for the first ten years of his life the boy and his whanau did not get the support and services they needed. How will the changes proposed in this Bill improve the situation for boys like the one in this story and enable earlier access to services and support, avoiding the need to be labelled "vulnerable".

We are concerned about the potential for disability to be equated with vulnerability. In order to access services, families may be put in the difficult situation of having to argue that their child or young person is vulnerable, highlighting their child's deficits and presenting them as tragically as possible; opening themselves up to assessments of whether they are providing a "safe, stable and loving" home and having their personal information shared.

IHC submits that the Bill needs to provide a legislative framework that ensures disabled children; young people and their families have timely access to flexible, integrated, quality services that advance their wellbeing and long term outcomes. IHC strongly recommends that the Chief Executive have specific duties in this regard.

Recommendation

IHC reiterates our recommendation that:

- The purpose section of the Bill be strengthened (specifically that section 4 (a)) to ensure children, young people and their families have timely access to flexible, integrated, quality services that advance their wellbeing and long term outcomes.

We further recommend that:

- The Bill include a duty on the Chief Executive to ensure co-ordination with other government funded disability and learning support services designed to improve the wellbeing of and outcomes for disabled children and young people.

10. Out of family care

IHC has long called for repeal of section 141 and 142 of the Children, Young Persons and their Families Act 1989 so that disabled children and young people could enjoy the same protections as non-disabled children when entering into out-of-family care including around legal representation, consent, review of placements and other arrangements and restrictions on full time residential care.

Our position has remained unchanged over the nearly 70 years of our existence. We believe that disabled children belong in their families and their communities, and that families should be well supported in their role with access to what is needed for a good life for them and their children.

IHC notes and welcomes information on MSD website that Intensive Intervention services will mean that “Parents of children with disabilities will have access to additional support to care for their child at home, and where these children can no longer be cared for at home, they will be provided with the same safeguards and rights as non-disabled children.”

Completion of the detailed design work on the new care system will be critical to ensuring disabled children, young people and their families are well supported so that children are able to know and be cared for by their parents and families in their communities.

Processes under s140 and s144 will also need to be adjusted to accommodate disabled children and young people and ensure their preferences and views are taken into account. (Please see our comments on participation above).

Recommendation

IHC strongly supports repeal of sections 141 and 142 as well as section 144(2) of the Children Young Persons and their Families Act 1989

IHC re-iterates its recommendation that:

- The Bill include a principle within section 5 that disabled children, young people and their families have timely access to flexible, integrated, quality services (so they can live together).

IHC further recommends:

- Section 144 of the CYFA be amended to require all children to give their consent to agreements for extended care, regardless of disability, either themselves or through an independent advocate.

Development of National Care standards

IHC strongly supports the requirement that National Care standards be established and would welcome the opportunity to contribute to their development.

As drafted the Bill does not specifically acknowledge and accommodate the rights and needs of disabled children and young people in care.

We suggest that the new section (fa) include specific reference to the rights and needs of disabled children and young people. These include rights to a live in a family type setting; ensuring review, advocacy, and complaints mechanisms are accessible to disabled children and young people and, if necessary, there are supports in place to ensure they enjoy the same protections as non-disabled children and young people in care.

Recommendation

IHC recommends that:

- The new section 447 (fa) include specific reference to the rights and needs of disabled children and young people, including their right to supports that ensure they enjoy the same protections as non-disabled children and young people in care.

11. Transition

IHC commends the provisions within the Bill extending support for those young people leaving the care system.

For young people within the care system with disabilities their need for support may be on-going. Some may need care into adulthood. It is not clear what consideration, if any, has been given to these young people or how the transition provisions will apply to them.

Other disabled young people in the care system will move to independence but may need additional support and assistance to do so.

We note and endorse the submission of CCS Disability Action that there is currently very little transition planning around a young person's living situation when they reached the end of their out-of-home placement.

IHC would like to see the need to take disability into account reflected in the principles governing the transition provisions in the Bill. We re-iterate that the Chief Executive should be responsible for co-ordinating with other government funded disability and learning support services to improve the wellbeing of and outcomes for disabled young people. This duty should extend to supporting disabled young people to transition from State care.

As with other Oranga Tamariki service areas, those working in transition services will need to have an understanding of intellectual disability and how best to support and assist disabled young people transitioning from care.

Recommendations

IHC recommends that:

- The Bill make it a duty of the Chief Executive to co-ordinate with other government funded disability and learning support services designed to improve the wellbeing of and outcomes for disabled children and young people.
- A principle be included in section 386AAC (clause 115) that disabled young people be provided with assistance and support to live independently, be included and participate in their community.
- Those working in the transition service area be trained in, and able to provide, appropriate assistance, support and guidance for those with intellectual disability transitioning from Oranga Tamariki care.

12. Youth Justice

IHC supports:

- moves to bring 17 year olds within the youth justice system;
- provisions to appoint, in certain circumstances, a youth advocate to represent a child or young person at an FGC (Clause 97); and
- clause 92, enabling referral to care, protection and wellbeing services under the Act.

12.1 Moves to begin bringing 17 year olds within the youth justice system

As noted earlier, young people with intellectual disabilities are likely to be over-represented in the youth justice system. Especially when their disability has not been recognised or they have not received effective support, disabled young people may have characteristics or traits, such as hyperactivity or low impulse control, that lead to offending.

Once young people are in the justice system their disability may make it difficult for them to understand the process. Research into intellectually disabled people's experience of the justice system has found that it can be an uncomfortable and frightening, and that communicating effectively and taking the time to listen to the young person's experiences and story, in order to understand how their disability may have contributed to their offending can help to ensure a fair response.³¹

The flexibility of, and principles underpinning the youth justice system, mean it is better placed than the adult justice system to hold intellectually disabled young people to account for offending, while recognising and accommodating their disability.

Currently New Zealand is out of step with its international obligations regarding youth justice and these changes will go some way to meeting the recommendation of the United Nations Committee on the Rights of the Child that New Zealand raise the age of criminal majority to 18 years³².

12.2 Appointment of youth advocate

IHC supports the appointment of youth advocates to represent the child or young person in family group conferences in cases involving offences punishable by imprisonment of 10 years or more. Given the over-representation of young people with disabilities in the youth justice sector, IHC would like to see training and support for youth advocates to ensure they are able to communicate with and represent a client with intellectual disability fairly and effectively. Research suggests this will require time getting to know the

³¹ Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates, Mark Henaghan *Developing a more responsive legal system for people with intellectual disability in New Zealand.* (2014) Donald Beasley Institute. Retrieved from <http://www.donaldbeasley.org.nz/resources/publications/law/>

³² CRC/C/NZL/CO/5. Committee on the Rights of the Child. Concluding observations on the fifth periodic report of New Zealand. Paragraph 45(b)

young person involved and listening to their story, a broad understanding of intellectual disability and the nature of the young person's cognitive impairment and having the skills to communicate effectively and check understanding.³³

12.3 Referral to care, protection and wellbeing services

IHC supports the principle (subsection 208(2), clause 92) that consideration be given to what supports might help prevent or reduce re-offending and whether a referral should be made to care, protection or wellbeing services.

In making this assessment regard should be had to whether the child or young person concerned has a disability and, if so, how this should be taken into account. As with other service areas disability awareness, training and supervision/support for those in the youth justice system will be critical to ensuring appropriate and cohesive responses to offending by disabled children and young people. (Please see recommendation ** above).

12.4 Custody

IHC notes and supports the Children's Commissioner's submission that the opportunity be taken in this Bill to repeal section 238(1)(e) regarding the detention of young people in Police cells.

As noted above, young people with disabilities are likely to be over-represented in the youth justice system. Detention in a Police cell is not appropriate for any young person, but it is particularly inappropriate and potentially even more harmful for a young person who has, by definition, limited ability to comprehend new things and who needs support³⁴.

Recommendation

IHC recommends that:

- The opportunity be taken to repeal section 238(1)(e) of the Children, Young Persons and their Families Act 1989.

³³ Above, n35.

³⁴ CRC/C/NZL/CO/5. Committee on the Rights of the Child. Concluding observations on the fifth periodic report of New Zealand. Paragraph 45(d)

13. Information sharing

IHC has significant concerns about the information-sharing provisions in the Bill and their ethical and practical ramifications for intellectually disabled children, young people and their families.

It is not clear that the changes are necessary to protect children from abuse or neglect. Issues raised by mandatory reporting would suggest that mandatory information sharing, especially given the override of duties of confidentiality, may well exacerbate risk of harm.

We are concerned that the proposed information sharing regime will create a powerful disincentive for struggling families who want to seek assistance, this will lead to more families reaching crisis point, and more children and young people may be harmed as a result.

While IHC supports data collection to track population based issues, ensure appropriate policy responses and evaluate impact, this can be done with anonymised data.

IHC understands that the provisions regarding sharing of datasets to identify groups of children (and with potential to identify individuals within that group) coupled with the wider grounds for care, protection and wellbeing are designed to enable intervention in the lives of groups of children who are identified as potentially “vulnerable”.

However, the proposed changes are potentially discriminatory and IHC believes that the ethical issues associated with this development have not been adequately consulted on, especially with the groups concerned, including disabled children, young people and their families and the organisations, like IHC, who work with them.

We completely support the broad policy intent to protect children from abuse and neglect and promote wellbeing, and we understand that those charged with intervening to protect a child from harm need to have full information on which to base their decision-making. However there seems to be an assumption that more people knowing more about a child will keep that child safer. IHC’s understanding is that the evidence on this is equivocal.

IHC submits that the information sharing provisions raise similar issues to those associated with mandatory-reporting and that greater consideration needs to be given to whether potential unintended consequences may undermine the Bill’s overall policy intent.

There is also a risk that sharing information will, in itself, be seen as a discharging responsibilities towards a child or young person of concern and serve as a substitute for reporting. There are many reasons why people minimise and refrain from reporting concerns about a child, for example fear of being wrong, concerns about making things worse and a lack of faith in how child protection agencies will respond. A presumptive information sharing framework may undermine existing reporting policies and protocols and reinforce existing reluctance to report.

IHC shares the specific concerns raised in the joint YouthLaw and ACYA submission and:

- the blanket override of duties of confidentiality (section 13 (j)) and the potential impact on trust relationships;
- the expanded scope of persons required to provide information;
- the mandatory disclosure framework, especially as it is being linked to funding³⁵; and
- the potential for the presumptive sharing framework (which includes datasets) to discriminate, stigmatise and label disabled children and young people or groups of children and young people.

As a service provider IHC notes and endorses the Privacy Commissioner's concerns that the information sharing provisions are "...complex and fragmented, lacking coherence and will be harder to understand than the current legislative regime."³⁶ We are also extremely concerned about the potential impact on the trust relationships with people using our services.

IHC contends that the current legislative framework allows for information sharing and that the issues undermining well-informed decision-making around a child's safety and wellbeing are largely practice based. While legislative change can influence practice, we submit that the proposed information sharing provisions are not justified as they are likely to do more harm than good.

That said, to reduce the risk of information not being shared due to uncertainty about whether to do so is legal we support immunity for disclosures made in good faith. For the same reason we would also support inclusion of an amended section 66C (clause 38) setting out and clarifying what information may be shared when.

Recommendation

IHC recommends that the existing Section 66 be carried over and consideration be given to inserting a new subsection into existing section 66 clarifying when information relating to a child or young person may be shared, in order to:

- assess risk of harm to that child or young person; and
- make or review a plan for that child or young person, including access to services; and prevent harm to that child or young person.

³⁵ See: <https://comvoices.org.nz/2016/11/24/the-collection-of-individual-client-level-data-cicld-issues-paper/>

³⁶ Privacy Commissioner, Media Release, 14 December 2016. Retrieved from <https://privacy.org.nz/news-and-publications/statements-media-releases/privacy-commissioner-comments-on-oranga-tamariki-bill/>

Appendix 1: New Zealand's internal human rights obligations UNCROC

New Zealand ratified UNCROC in 1993. UNCROC covers all those aged up to 18 years of age³⁷ and all areas of children and young people's lives:

- Civil rights and freedoms
- Violence against children
- Family environment and alternative care
- Disability, health and wellbeing, including standard of living
- Education, leisure and cultural activities
- Special protections for indigenous and minority groups of children, child victims, young offenders and children who work.

UNCROC has four general principles which need to be taken into account when considering specific rights such as those regarding protection from violence, care and contact with the legal system. All children have the right to:

1. non-discrimination, including on the grounds of disability (Article 2);
2. have their best interests be the paramount consideration in all actions concerning them (Article 3);
3. life, survival and development; and
4. express their views and have those views taken into account, and to be heard in any proceedings.

Two other articles are regarded as cornerstones of UNCROC and a child rights approach. Article 5 affirms the right of the child to be guided by their parents, extended family and community in the exercise of their rights.

Taken as a whole, under UNCROC there is a presumption that children and young people should be raised by their birth parents, within their wider family and community unless there are good and lawful reasons for them not to be. The following article speaks to this point:

- Article 7 children and young people have the right to know and be cared for by their parents "as far as possible".
- Article 8.1 requires States to respect the child's right to preserve his or her identity including nationality, name and family relations "as recognised by law without unlawful interference".
- Article 9.1 provides that a child should only be separated from his or her parents when "...competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child". Separation may be necessary in cases of abuse and neglect.
- Under Article 9.3 children have a right to maintain personal relations and direct contact with both parents on a regular basis unless it is contrary to the child's best interests.

³⁷ Children unlawfully in New Zealand are specifically excluded from the Convention's coverage by virtue of a general reservation. New Zealand also has in place reservations that allow children to be detained with adults and which assert the adequacy of current protections for children who work.

- Article 10 sets out the child's rights with regard to cross border family reunification, re-enforcing the principle that children should be raised within their families wherever possible.
- Article 18 recognises that both parents are responsible for raising a child and States are obliged to provide appropriate assistance in child rearing.
- Article 27 recognises the child's right to an adequate standard of living. Parents (or others responsible for the child) have primary responsibility to provide that standard of living but States are obliged to assist, including through material assistance and support programmes, particularly in relation to nutrition, clothing and housing.

Article 4 requires States to undertake all appropriate legislative, administrative and other measures for the implementation of UNCROC. This requirement is absolute for civil and political rights, such as those to do with privacy. With regard to economic, social and cultural rights States are required to "...undertake such measures to the maximum extent of their available resources..."

Articles 19, 20 and 23 are particularly relevant to this submission. Article 19 sets out children's rights to be protected from violence and abuse. Article 20 says that children are entitled to special protection and assistance from the State when deprived of their family environment.

Article 23 specifically recognises the rights of intellectually disabled children and young people to "...enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community." It goes on to cover the disabled child's right to care and assistance and to access education, health and other services and to enjoy recreation opportunities.

UNCRPD

New Zealand ratified the UNCRPD in 2008.

One of the UNCRPD's general principles is respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Under Article 7(1) of the UNCRPD New Zealand agreed to take "all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children". New Zealand has therefore agreed to do all it can to ensure all the rights of disabled children and young people are protected and advanced.

In particular:

- in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration; and
- children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.

Under the UNCRPD, as far as possible, children have a right to know and be cared for by their parents (Article 18(2)). Under Article 23 New Zealand has undertaken to:

- ensure children with disabilities have equal rights with respect to family life
- provide early and comprehensive information, services and support to children with disabilities and their families;
- ensure children are not separated from their parents, against their parent's will, except when "... competent authorities subject to judicial review determine, in accordance with applicable law and procedures that such separation is necessary for the best interests of the child."; and
- when the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

New Zealand is also obliged to have effective child-focused legislation and policies in place to ensure that exploitation, violence and abuse are identified, investigated and, where appropriate, prosecuted.

IHC strongly supports and applauds the inclusion of the new section 5(a)(i) requiring respect for children and young people's rights with specific reference to UNCROC and the United Nations Convention on the Rights of Persons with Disabilities.

Appendix 2: Shifts in thinking about disability.

Shifts in thinking about disability	
FROM	TO
Disability is an individual problem	Disability is a problem in society
Differences in abilities are inadequacies	Differences in abilities are assets
Seeing deficits	Seeing strengths
Us and them: exclusion - tolerance	All of us: inclusion - valuing
Society choosing for 'them'	Disabled people choosing for themselves
Professionals know best	People have different kinds of knowledge
Charity based	Rights based
Patient	Citizen
Institutional orientated	Community orientated
Medical model of disability - control or cure	Social model of disability - change environment and attitudes

Office for Disability Issues, Ministry of Social Development.
<https://www.odi.govt.nz/about-disability/shifting/>

Appendix 3 - “True story from a Children’s Team”.

This is an analysis of an item in the December/January 2016/17 Children’s Action Plan newsletter. It is available here:

<http://childrensactionplan.govt.nz/assets/Uploads/CAP-Newsletter-December-January-2016-17.pdf>

Given the number of children’s teams and the numbers of families dealt with under children’s teams it is not beyond the realms of possibility that the boy involved could be identified by this story. We trust the permission of the boy and his mother was granted before publication.

The first paragraph describes the boy in the following terms: “He had significant behavioural issues and enuresis, asthma and ADHD. He had significant learning developmental delay and struggled to socialise at school. Although his attendance was good, he would often come to school unclean and unkempt. He was already getting additional support in school but this was not effective.”

The article goes on to describe the mental health of his mother and that she had been charged with assaulting her son. It explains that 19 agencies were involved with the whānau for a long time with little effect and talks about no respite carer being willing to take the boy, the school not being able to manage him and his mother having to give up her job in order to keep up with the large number of appointments and manage the difficult relationship she had with the school, including often being called to pick her son up early.

In short, the article presents the boy and his family negatively, as a problem to be fixed.

After referral to the Children’s Team and the identification of a Lead Professional there was better co-ordination of services and supports for the whānau, including a consistent approach to managing the boy’s behaviours at home and at school. The boy attended health camp, his self-confidence and ability to manage his behaviour and enuresis improved, as did his social relationships. He became involved in sports and kapa haka. *“His speech and language have improved dramatically and he has jumped two years in reading level.”*

The article concludes “Through the coordination of the Children’s Team approach there are now fewer organisations involved with this family. The boy has progressed so much that CAMHS [Child and Adolescent Mental Health Services] have since discharged him, and Child, Youth and Family are no longer involved.

The Children’s Team is still involved in order to secure suitable respite care and embed the changes and progress made by this family.”

The boy in the story was ten years old when he was referred to the Children’s Team. It begs the question as to why, for the first ten years of his life, all the agencies involved with this boy and his whānau failed them.

Towards the end, the article notes that a psychological assessment found that the boy had an intellectual disability. It is reported that this diagnosis enabled the mother

to get additional respite care. There is no indication that any accommodations were made for his disability by his school or the other services he was involved in. Neither is it explained why this assessment had not been made earlier.