



## **IHC Submission**

# **Inquiry into the Determinants of Wellbeing for Maori Children**

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Call to Action: What needs to change for children and young people with disabilities and their families?

Start Strong Action Plan

## 1. About IHC

### **Mission Statement:**

***IHC will advocate for the rights, inclusion and welfare of all people with an intellectual disability and support them to lead satisfying lives in the community.***

IHC New Zealand Incorporated (IHC) is a community-based organisation providing advocacy and support for people with an intellectual disability and their families. IHC advocates for the rights of the thousands of New Zealanders with an intellectual disability. IHC has 4500 financial members representing families, people with intellectual disability and self advocates. Through our service arm, IDEA Services, IHC works with around 3000 children with an intellectual disability and their families.

IHC has a long history of responding to the needs of families and is committed to non-government funded programmes of work related to individual and systemic advocacy, empowerment of individuals and families and the inclusion of people with intellectual disability in society. Our current Start Strong initiative and publication Call to Action: What needs to change for children and young people with disabilities and their families; highlight the actions required to ensure that disabled children and their families are able to access early and sustained support and have their rights recognised and responded to.

IHC's work is guided by the principles of the Treaty of Waitangi, the New Zealand Disability Strategy (NZDS), the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCROC).

IHC would welcome the opportunity to clarify or provide further information on the matters we have raised in this submission.

## 2. Introduction

IHC welcomes the opportunity to make a submission to the Maori Affairs Select Committee Inquiry into the Determinants of Wellbeing for Maori Children.

In this submission IHC has restricted our comments to matters about which we have some expertise; i.e. intellectually disabled children. In our view it is imperative that the inquiry into determinants of well being for Maori children considers the particular needs of Maori children with an intellectual other disabilities, and their whanau. IHC has strong links with other disability support organisations, including CCS Disability Action, Parent to Parent, the New Zealand Down Syndrome Association and others. IHC is confident our submissions about what needs to change for Maori children with an intellectual disability, holds true for all Maori children with a disability.

People who identify as Maori are almost 13% of New Zealand's population according to the 2011 Ministry of Health publication Health Indicators for New Zealanders with an Intellectual Disability. The same publication reports that 16% of the population of people with an intellectual disability are Maori and that people and particularly children with an intellectual disability are more likely to be male and these boys are more likely than girls to have behavioural and developmental problems that bring them to the attention of support services.

IHC strongly believes that Maori children with disabilities should be valued as children first, with their rights respected and responded to on an equal basis as non disabled Maori children and of course all children in general. Too often, however, this is not the case with children with disabilities being cast as 'other', being seen as having lives of less value and their rights being violated. This means disabled Maori children often experience a double whammy, "other" due to their disability, and "other" because they are Maori.

Extreme examples of the devaluing of disabled children's lives to the point their lives could be taken was seen in the reaction of the media and New Zealand public to the murders of two disabled children Casey Albury in 1997 and Baby C in 2004. The focus of media attention and public sympathy was with parents and the dreadful burden they had to supposedly bear; not on the rights of the disabled child to survival and the lives of all children to be valued regardless of disability.

In this submission IHC reports that many Maori children who are disabled do not thrive, belong or achieve as well as their non disabled brothers and sisters, because of their disability. Maori disabled children become vulnerable when their whanau do not receive early, sustained, flexible and integrated across government agency support which is child and family centred and when they experience isolation and barriers to inclusion in their communities.

International researchers suggest that children with disabilities may have increased vulnerability to abuse because of society's response to the disability, rather than the disability itself. Children with disabilities are perceived as less valuable than other children. Their reports of abuse may not be considered trustworthy. Discipline may be more punitive and accompanied by a lack of respect. Other factors leading to abuse among children with disabilities are the same as those found in the general population, i.e. single parents, teen parents and various levels of stress. Maori are over represented in these risk indicators.

The whanau of children with disabilities can experience additional stressors including feeling unprepared to handle the necessary additional care requirements of a disabled child, acceptance of that child as being "different", having already limited resources stretched as additional medical and educational activities are suggested, and lacking necessary social supports or networks to work through the many concerns and situations that arise in providing care for the disabled child alongside the rest of the family. These stressors can result in increased vulnerability to abuse. A child with difficult to handle behaviour patterns, or communication difficulties, may become a target for physical abuse. Children who are unable to communicate their needs may experience greater instances of neglect. There is a risk that the disabled child may develop extensive relationships of trust with greater numbers of people such as formal and informal caregivers, and be unable to distinguish when boundaries are being crossed, resulting in potential sexual abuse.

The 2005 United Nations report on Violence against Children found that violent abuse incidents against disabled children occurs at least 1.7 times more often than against their non disabled peers.

In already violent households, the presence of a child with a disability often compounds and intensifies the nature and extent of the abuse. A mobility impaired child cannot flee, a deaf child may be unable to communicate the abuse to the outside world, an intellectually disabled child may be less able to anticipate and read the warning signals that violence is about to occur and may be unable to escape or hide.

Researchers suggest that parents may become violent toward the disabled child, not because they are reacting to the child's disability, but because of the social isolation and stigma they experience from the wider community as family and friends distance themselves and because social services and supports are limited and local schools are unwilling to enrol their child.

Parents may respond to the stress of raising a disabled child with neglect rather than active violence. For example, a disabled child may become malnourished because no one takes the time to feed them adequately or untreated bedsores can result in potentially deadly infections.

Families, neighbours and social service agencies may not intervene as readily, as they rationalise that the stress of the parent is understandable and they may struggle to access alternative arrangements. The United Nations report, recommended that countries target the abuse experienced by disabled children by ensuring the inclusion of disabled children in general as well as disability-specific violence prevention programmes, fostering increased awareness of violence against disabled children. The report highlighted the need for government leadership to reduce violence, to be reflected in legislation and the enforcement of existing laws and that protection of disabled children should extend across ministries with welfare, health, education and others, working cooperatively to provide oversight for disabled children at risk, as part of what happens for all children. Tracking of children through workable, comprehensive reporting mechanisms is critical as are public education programmes which ensure inclusion of disabled children in schools and communities. In addition disabled children should have access to appropriate rehabilitative supports such as counseling when they have been victims of abuse.

The whanau of disabled children and disabled children themselves must be empowered to advocate on their own behalf. IHC's submission draws from information gathered from the experiences of IHC's Advocacy Team, IDEA Family/Whanau and

IDEA Specialist Services and consultation with families and family membership organisations as part of the Start Strong campaign to improve early support for disabled children and their families. IHC's publication; Call to Action: What needs to change for children and young people with disabilities has also informed our feedback on the Green Paper as well as this submission. The Call to Action and Start Strong Action plan are attached to IHC's submission.

Disabled children can be vulnerable merely by virtue of their disability. They can experience threats to their survival and wellbeing and experience a lack of valuing and belonging. Many other disabled children and their families become vulnerable because of difficulties accessing early, sustained support which is flexible, timely, integrated and culturally responsive, and when they are not included in community. For Maori whanau already under the stressors of poverty and marginalisation there may be increased risks for their disabled children.

The information presented within IHC's submission identifies that many disabled children in New Zealand experience the same vulnerabilities as described within the United Nations report. IHC requests that further focused consideration is given to disabled children within the government process aimed at better responding to the needs of vulnerable children.

IHC submits that the community of Maori disabled children and in particular the almost 3000 Maori children and young people with an intellectual disability, are even more vulnerable than non Maori disabled children, because of the disadvantages experienced by the Maori population in general.

### **3. The historical and current health, education and welfare profiles of Maori children - IHC focuses on disabled Maori children**

Being Maori should not be synonymous with being sick, poorly educated, unemployed and disadvantaged. Neither should being disabled. Parents and whanau have told IHC that, not only do Maori children experience disadvantage, but that their disabled brothers and sisters experience even greater disadvantage and therefore greater vulnerability.

Actions must be taken to ensure that Maori children can flourish and grow. Decision makers must ensure that disabled children are not regarded as “other”, and outside of these initiatives. Children with disabilities are children first and have the same needs, hopes, dreams and rights as all children. Disabled children gain the same benefits from being well loved, being in safe caring environments, and having good access to healthcare and education. Many parents and whanau who are responsible for the nurture and support of Maori children are already in a precarious position.

Children living in disadvantaged and impoverished circumstances are at increased risk of experiencing poor health care, food and housing, reduced educational opportunities, poorer cognitive development, and have a greater exposure to instability in living arrangements, dangerous environments, violence, and adult drug and alcohol use.

New Zealand is one of the most poorly performing OECD countries in terms of health and wellbeing for children, We rank 28<sup>th</sup> out of 30 countries. New Zealand has a low rate of investment in children- we spend less than half the average OECD public spend on children aged less than six years. This has high downstream costs in health, crime, remedial education of about \$6 billion. That's 3% of GDP. In two decades New Zealand has gone from being one of the most equal societies to one of the least equal than any other OECD country. Children who live in households with low family income experience poor health and have poorer long-term outcomes. Over 200,000 New Zealand children live in benefit dependent households. 26% of New Zealand children were living in sole parent families in 2006. New Zealand has more sole parent families than any other OECD country other than the USA and Maori are disproportionately represented.

The picture for New Zealand children with a disability is even more grim: 25% of children with a disability live in benefit dependent households, 28% of children with a disability live in one parent homes, 18% of children with a disability live in homes where the income is less than \$30,000 per annum. Only 25% of disabled children aged younger than 14 are estimated to be receiving special education support. When 25% of unemployed and 50% of DPB beneficiaries are Maori or Pasifika; there is a high likelihood that if you are a disabled Maori child you come from an impoverished home

The negative impact on well being is compounded when children and their families are not connected to social and cultural supports or their communities. A child with a disability may cause the family to be shunned and excluded, treated as “other”, creating isolation from the natural supports that is experienced by most families. Isolated, impoverished parents with limited social and community support are at especially high risk for maltreating children with disabilities, because they may feel more overwhelmed and unable to cope with the care and supervision responsibilities that are required.

Every child does not have the same starting point and children who are disabled are not all equally disadvantaged. Children and young people with disabilities are

susceptible to the same risks as all children. However having a disability or significant health problems is a significant contributing factor to vulnerability. Children with chronic illnesses or disabilities can place higher emotional, physical and social demands on their whanau. Lack of respite or breaks in child care responsibilities can contribute to increased risk of abuse and neglect. These difficulties compound when parents and whanau feel not welcomed and treated as 'other' by mainstream services. Isolation can increase risk to children because there are fewer "eyes" monitoring their safety and well being. For Maori accessing culturally appropriate supports is an additional stressor and often overwhelms already stressed parents and whanau.

There are four main areas where Maori children with a disability and their whanau experience particular disadvantage.

### **3.1 Health:**

There is considerable evidence of inequities between different ethnic groups within New Zealand. The effects on Maori children with disabilities can be seen in differences in socio-economic conditions, housing, educational attainment and health status. There are higher rates of death and disease among Maori children when compared with non Maori children. Maori children are more likely to die from SIDS (cot death) respiratory conditions and infectious diseases, less likely to be immunised, more likely to be admitted to hospital for respiratory conditions, injuries and poisonings and communicable diseases and more oral health problems.

Where families do support their children and young people with disabilities there is a lack of financial support, and access to any other supports such as respite care is a constant and often overwhelming challenge that daunts even the most determined.

Minister Turia was quoted in the Gisborne Herald 15 Nov 2011 as saying it was wrong that family members were not paid to act as caregivers when the state happily paid strangers to do the same work.

"We have a lot of families who take care of their own at huge expense and stress." Ms Turia said. "The Ministry of Health always used 'the excuse' that it did not want families to regard that sort of care as income. It's a spurious argument because they don't mind someone else doing it. I feel outraged they're prepared to take advantage of family members by using these arguments that don't wash."

IHC believes Minister Turia's comments reflect the views of whanau with disabled children. Her sentiments have been echoed at our Start Strong and other forums.

### **3.2 Education:**

Children with disabilities and long term health issues experience significant inequalities in early childhood education, the primary and the secondary school system and in the transition to work.

Maori children, alongside other disabled children, are over represented in school suspension and expulsion statistics. They are three times more likely to be suspended and twice as likely to be stood down when compared to non Maori students. The exclusion and expulsion rate of children with identified special education needs is also very high. A large proportion of students excluded or expelled from school are not

returned to a mainstream school environment and may become disengaged from education altogether.

Maori children with disabilities may only be able to access schools and early childhood services for limited hours and may miss out on wider curricular activities and the sense of belonging within the educational community. Parents attempting to choose inclusive education report instances where children are not given the same opportunity to learn as their peers. For example attendance may be limited, parents may be asked to contribute to teacher aide hours or enrolment may be refused altogether. There are issues for children with disabilities transitioning between early childhood services and schools, resulting in extreme parental distress and frustration due to a fragmented approach to funding and entitlements.

The UN Committee on the Rights of the Child was concerned that New Zealand children with disabilities were not fully integrated into society and those services, in particular education services were often difficult to access. The committee recommended that the Government ensure there were sufficient resources to implement the NZ Disability Strategy and in particular aspects related to the integration of children with disabilities into mainstream education. While legislation and government policy is in place to enable children with disabilities to enrol in their local school it is often extremely difficult for families to have their disabled child enrolled at their local school. IHC has numerous examples of children being “turned away”. This has formed the basis of the IHC discrimination complaint to the Human Rights Commission. The Herald on Sunday editorial of 4 March 2012 said that they had been swamped by stories of families of disabled children who reported having been “turned away” from their local school.

### **3.3 Welfare**

The general lack of understanding of issues for children and young people with intellectual disabilities is often manifested as a lack of understanding about the difficulties for these children and young people, particularly as it relates to their ability to communicate, the frustration at not being understood (hence manifestation of difficult to manage behaviour); their high support needs i.e. autism and their existence in a world where the social arrangements are organised for a “one size fits all” way of seeing the world

Very limited financial support for families of children and young people with disabilities and poor resourcing and availability of other supports has led to growing numbers of children being placed in institutional type of living arrangements. This also occurs for children without disabilities when they are considered too difficult to place within the community. While there are not a lot of community options for children with disabilities, even when such opportunities are provided by agencies, there is still a tendency to place these children out of their communities in residential placements. IHC uses the term institution to refer to a placement outside the child’s community; and/or where the place where the child lives follows the rules of the house rather than meeting the child’s needs.

While the departments of Child, Youth and Family (CYF) and the Ministry of Health (MOH) have developed a memorandum of understanding for children with disabilities and care and protection needs there still seems to be a siloed approach when it comes to supporting children who have high and complex support needs. Disability can overshadow care and protection issues when brought to the attention of CYF resulting

in the original care and protection issues not being attended to. Disabled children can be treated differently to non disabled children. IHC knows of many cases which evidence not only a lack of communication between agencies, but more costly out of home care options being put in place.

Children with disabilities in foster care are at greater risk of abuse and are less likely to be reunited with their family of origin. There are over 500 children with disabilities under the care of CYF and in care and protection placements outside their home.

IHC believes that 10 – 20% of children in out of home care are disabled and we suspect that they are disproportionately Maori. Their removal from whanau, hapu and iwi puts these children at even greater risk as they move into adulthood, isolated and lacking identity and a sense of belonging which is fundamental to a sense of wellbeing.

IHC believes that there is a general lack of understanding of the provisions of the care and protection legislation as it relates to children and young people with disabilities and also a general lack of understanding of children and young people with disabilities. The separate provisions for children with severe intellectual disabilities (section 141) and children with disabilities (section 142) of the Children, Young Persons and their Families Act, 1989, contribute significantly to this situation. These two sections reflect broader societal views that whanau cannot look after their children when they have severe disabilities and endorses some views held that parents and whanau should not be expected to look after their children with disabilities.

### **3.4 Justice**

Access to justice is another issue for young persons with disabilities. Youth were not initially thought to be considered under the 2003 Intellectual Disability Compulsory Care and Rehabilitation (IDCC&R) Act, but it is of enormous concern that young persons with disabilities are increasingly being charged and incarcerated under this Act. Young Maori males feature disproportionately, and are being charged and incarcerated. Disturbingly many of these teenagers are being recognised as having an intellectual disability when they come before the courts for the first time and until their court appearance have been unknown to any disability support services. Clearly the needs of the child and their whanau have, until that time, been unrecognised by health and educational agencies. It is possible that they have been perceived as Maori and there has been an acceptance or expectation that their behaviours and lack of achievement in educational settings are related to their ethnicity, with disability not being considered and no supports being put in place.

It has been of enormous concern that only in the last twelve months has the Ministry of Health developed appropriate secure facilities for children with intellectual disabilities who have been charged under the Act or who need to be contained for their own protection or the protection of the community. IHC has no data available to have an understanding as to whether the new facilities are sufficient for this growing population of incarcerated young people with intellectual disability. We are also unable to comment on cultural appropriateness of this service.

- 4. The extent of public investment in Maori children across the Health, education, social services and justice sectors and whether this investments is adequate and equitable;**

and

- 5. How public investment in the health, education, social services and justice can be used to ensure the well-being of Maori children**

IHC is encouraged that the Government has signalled a long term commitment to improve outcomes for vulnerable children. As a country we know a lot already about what works well, what can be built on and what needs to improve. IHC hopes the government's forthcoming White Paper will indeed result in a long overdue whole of government approach with the cross party support that is needed to progress and sustain meaningful change. IHC is heartened that 8800 New Zealanders were so concerned about vulnerable children in New Zealand that they made submissions on the Green Paper for vulnerable children.

IHC endorsed the Green Paper's child-centred focus and emphasis on the importance of early support and intervention for children, their parents and whanau. Equally important are early responses to any problem or issue that emerges in the course of a child or young person's life. We are also pleased to see that attention is given to strengthening and working in partnership with families, whanau, hapu, iwi and communities. Key areas of leadership, policy and practice were identified as the foundation to ensuring timely and effective cross sector actions. Other critical components of the discussion include consideration of how to better share information, implement evidence based practices and build workforce capacity.

The Green Paper's introduction acknowledged that growing up in poverty is associated with poorer outcomes for children. IHC is concerned that the Green Paper, with its focus mainly on services and programmes for vulnerable children in the proposals made and questions asked, is silent on addressing poverty and reducing inequities.

IHC notes that since the release of the Green Paper the government has set up a taskforce on poverty. Clearly it is of utmost importance that these two government priorities are linked and that the issues which create and impact on, vulnerable children are considered within the wider context of poverty and inequity. Vulnerable children are a subset of all children and this wider context provides the base that is supportive of child well being with universal measures to help all children do well on which targeted measures to reduce risks to those most at risk and quality assistance for those in difficulty sit. This is proportional universality and is used in the Australian and Scottish models cited in the Green Paper.

The Government justified the narrow focus of the Green Paper by saying that "other Government-led work is happening in this space" and adds "there is already substantial investment by Government in children and their families and whanau across the economic, transport, health and education sectors and more".

IHC is not reassured, however, that this will be sufficient to bring about the greater integration that is needed and consider that the Action Plan for Children as proposed by the Commissioner for Children should encompass specific measures where needed for children in vulnerable circumstances. The Green Paper recognised having a disability and/or significant health problems among risk factors for vulnerability and

also spoke of the additional supports that may be needed for parents of children with challenging behaviour or disabilities.

IHC suggest that an Action Plan for **all** children is required with specific actions for children in vulnerable circumstances and that Maori children, disabled children and disabled Maori children all require specific consideration and actions. The varied needs of children with disabilities and their parents and whanau span several sectors and, as reported in the recent PHAC Report supports often are not well integrated or sustained resulting in disjointed care and early education. The PHAC report highlighted New Zealand's low investment in the early years in comparison to international standards and identified significant systemic issues in poorly coordinated policies and service delivery that negatively impacted on all children and their families. They, however, considered that families of children with high and complex needs or disabilities were among those most affected by such incoherent policies and services having to face navigating their way through inconsistent information and disjointed service delivery.

## **6. The social determinants necessary for healthy growth and development for Maori children**

All parents and whanau of a disabled child need support at times; whether informal or formal. IHC has a strong commitment to a Whanau Ora approach. The whole basis of our Start Strong campaign is that disabled children will have the best possible futures if they have the best start in life and the heart of Start Strong is connectedness. Parents and whanau must be connected with support, connected with services, connected with transition and connected with knowledge.

### **6.1 Whanau need to be connected with support**

Whanau must feel supported, be part of a network and be connected with the information and support they ask for.

Typically parents have to repeatedly tell their child and their whanau story and give the same information to enable them to be able to access services. Whanau with disabled children often have to “fit” with what is available within the constraints of contracted programmes rather than have more individually tailored responses that better meet the needs of the child and their whanau. Too often the services that are obtained are fragmented and parents find themselves having to co-ordinate and juggle appointments between multiple agencies, health, education and childcare providers. Some parents talked of wanting a central place where they could coordinate appointments to see a number of professionals and/or having coordinated home visits. IHC suggests that early childhood centres and schools should be considered by all agencies as an appropriate venue for coordination of appointments.

Whanau talked about having to become the “expert” on their child’s disability and being their child’s “therapist” because no-one else has the knowledge or is able to provide the practical assistance. As identified by the PHAC (2010) families report the lack of coordination within and between services and inefficiencies in communication makes for poor use of resources.

*Example: Agencies working in partnership - Community Living Trust (CLT) and CYF*

The service provides for support for children, young people and/or their primary caregiver with a confirmed diagnosis of a disability and/or children, young people and/or their primary caregiver with a confirmed mental health diagnosis. The partnership between the CLT and CYF has reduced the need for CYF to take status for referred families. The disability liaison professional working in CLT and funded by CYF ensures generic services are appropriately engaged and as well as needed disability service supports.

Identified strengths of the service are:

- Consistency of one key worker supporting families and liaising/working with CYF
- Strengths based comprehensive plans that are developed with families and involved agencies and that are navigated, monitored and reported on back to CYF
- Careful transition of families to a new lead agency minimising potential future reports of concern to CYF

- Ability to have one agency able to work across both the disability and mental health sectors
- Building and maintaining relationships with relevant social services with consent of the family

Benefit of the service for families:

- Working alongside families strengthens their ability to return back to the “driver’s seat” and retain control over their lives.
- Having time to focus on disability needs as well as on care and protection needs enables families to make informed choices
- Tailoring services and supports to families acknowledges their diversity
- Being the ‘key worker’ helps families to get connected/reconnected with services, natural supports and local community

Providing advocacy in crisis situations supports families to get access to assistance

## **6.2 Whanau need to be connected with services**

Children with a disability must receive timely, quality integrated services and support.

Having an identified key worker/contact person is viewed as an effective way to improve coordination and build trusted relationships with families that allow the “difficult conversations” to be had. There are differing definitions of what being a key worker entails, however, core features include being a contact point and source of support to the whanau and working in partnership to facilitate co-ordination and planning and delivery of supports. Local area coordinators as proposed in the Ministry of Health ‘new model’ may fulfil this role but to be effective this needs to be grounded in a community development model that integrates across the health, social development and education sectors. This type of role should not be used to gate keep access to funded supports.

There is clearly a need for the development of workforce capability and capacity within children’s services, mainstream providers and early intervention specialists and increased use of evidence based practice to ensure and enable provision of high quality support.

As part of achieving children with disabilities being included in the community of all children, they and their whanau need to be welcomed and appropriately responded to by Well Child/Tamariki Ora services and early childhood care and education providers. A number of parents have told IHC of having to continually fight for their child’s inclusion or receiving inadequate medical care. Whanau want services to be respectful of cultural differences and diversity with culturally competent practices.

As reported in the 2011 report prepared for Every Child Counts by Infometrics – 1,000 days to get it right for every child; New Zealand

- is one of the most poorly performing countries in the OCED in terms of outcomes for children (28<sup>th</sup> out of 30 countries);
- has one of the lowest rates of public investment in children; and
- the investment New Zealand makes, ranks as one of the least effective.

IHC recognises the constraints in the current environment and acknowledges that there are a number of areas where better use could be made of existing resources as well as areas that require greater investment.

### **6.3 Whanau need to be connected with transition**

Whanau must receive help with transition into early childhood centres and schools and later into adult support services

The varied needs of children with disabilities and their families span several sectors and as reported in the recent PHAC Report supports often are not well integrated or sustained resulting in care and early education becoming disjointed. The PHAC report highlighted New Zealand's low investment in the early years in comparison to international standards and identified significant systemic issues in poorly coordinated policies and service delivery that negatively impacted on all children and their families. PHAC considered that families of children with high and complex needs or disabilities were among those most affected by such incoherent policies and services and having to face trying to navigate through inconsistent information and disjointed service delivery.

### **6.4 Whanau need to be connected with knowledge**

Having information is a first step but getting early supports in place are often extremely difficult and time consuming process for parents and whanau.

Despite being armed with knowledge about the benefits of early support whanau may find that they may not be able to obtain the necessary services or cannot access services and support it in a timely manner or that the time that they are able to get support for does not adequately meet their child's needs and/or is not equitable with provisions for non disabled children. The unavailability of proactive services or long waiting lists run counter to the intent of achieving accessible, high quality early supports. A lack of early supports may also exacerbate the numbers who reach a crisis point and result in more complex and costly intervention and an increase in problems for the child and their family.

In the seminars and discussions IHC hosted for the Start Strong campaign parents and whanau identified the need for greater responsiveness, flexibility and coordination than that which they frequently experienced.

There are different ways to achieve coordination which may range on a continuum from networking which involves sharing information, to coordination which adds altering activities to achieve a common purpose to cooperation which adds formal links to collaboration which adds working together for mutual benefit.

## 7. The significance of whanau for strengthening Maori children

The IHC Start Strong seminars profiled some good examples of innovative practice in working with disabled children and their whanau. Unfortunately the agency concerned is finding this positive example of good practice difficult to sustain because of inflexible contracting arrangements and silo disputes.

IHC will continue to campaign for a whanau approach through our Start Strong campaign. IHC has heard of local practices developed by Maori staff in agencies such as Northable and CCS Disability Action which have struggled for recognition and adoption across New Zealand. IHC is concerned that the Ministry of Health has turned to overseas models to trial and develop with the approval of their Ministers.

*Example: CCS Disability Action Supported Lifestyles (Bay of Plenty and Waikato)*

The Supported Lifestyles Service has received two positive independent evaluations, the first in 2005 in the early stages of the service and the second in 2009 (Espiner, 2009). The primary outcome sought from the service is to increase individual, family and whanau wellbeing, connections and community involvement. Service delivery depends on individual, family and whanau needs, thus the intensity, duration and frequency of support varies from person to person and changes over time. A critical element is having a key worker role that stands alongside families and assists in coordinating flexible and individually responsive supports. The service has a Maori team who work with whanau, hapu and iwi.

Families particularly valued

- trust in the relationship
- responsiveness
- having key workers who believed in them and their expertise in caring for their child.
- the great 'back up' provided by the service
- getting up to date information and advice
- the ability to access services they wouldn't otherwise have known about or believed they could not access.
- being involved in planning and decision making
- key worker assistance to use their resources creatively
- having staff who are Maori with an understanding of and ability to work with tikanga Maori

Key features that led to good outcomes

- Long term relationships, families come in and out of the service
- Holistic focus, focus on individual and family needs and solutions
- Maori team who work with whanau, hapu and Iwi
- Build relationships so that the hard conversations are possible
- Access to service not totally dictated by contracts
- Their role in systems navigation, opening gates
- Future planning

## **8. Policy and legislative pathways to address the findings of this inquiry**

IHC concurs with the Children's Commissioner's view (as expressed in his response to the government's Green Paper) that the CYF Act, 1989 provides a sound legislative platform for balancing the roles of parents, whanau and children. However IHC strongly believes disabled children should not be treated differently under the legislation and recommend that the Act be amended by removing sections 141-146. Disabled children should not be discriminated at a legislative, policy or practice level.

Current practice, results in disabled children being moving into out of home, and often out of their home community placements with no legal representation or statutory oversight. As referred to in the previous section disabled children can be viewed through a disability lens and not a care and protection lens when they come to the attention of the CYF. The current memorandum between CYF and MOH does not routinely result in practice which recognizes the rights of disabled children to ongoing connection with their whanau and community.

Families have told IHC that mainstream children's agencies in communities are not always responsive to disabled children. Maori report that mainstream children's agencies are not culturally responsive for their children. There is a need to increase the capacity of these agencies so that responsibility is shared and disabled children are rightfully part of the community of all children.

IHC supports the Children's Commissioner's published position on the need for an improved interagency focus on neglect and the need for the Government to review its approach to investing in community led development.

IHC supports the need for a Children's Action Plan which has statutory underpinning for accountability and measurement of progress purposes. We also support the need for child impact assessments, annual progress reports by an independent crown entity and alignment with the UN Convention on the Rights of the Child.

In addition we support the need for specific targets to be established for disabled children in addressing child poverty and protecting children from all forms of abuse and exploitation.

IHC supports the position of the Children's Commissioner on working with whanau, hapu, and iwi.

IHC wants government to model collaborative, integrated approaches and across government agency funding packages to ensure that community support services are not constrained by inflexible and contract silos.

Child-centred policy is required that supports and enables collaboration across sectors and with families, better connections within communities, a life course approach which prioritises early and sustained support.

IHC endorses the principles proposed by the Children's Commissioner for prioritizing resource allocation. In addition IHC supports cost benefit analysis throughout at planning stages, which is publicly available so that informed decisions can be made.

IHC supports the provision of universal services but balanced with services of varying intensity matched to different populations of need. As advocated for in the IHC Start Strong campaign funding emphasis must be placed on early intervention services which save money "down stream"

Delays in access, lack of responsiveness to individual learning needs and disjointed and uncoordinated services can result in an inefficient use of resources and a poor return in investment. For some children and their whanau these issues mean that early supports are not put in place and nor are actions taken that could prevent an increase in problems for the child and their whanau, causing more complex and costly interventions to be required later. There should be an emphasis on proactive support particularly in the areas of communication and behaviour.

IHC believes that Government needs to address with certainty the funding barriers to providing services to all children and specifically to vulnerable children. Agencies which respond to children currently have to operate within multiple sectors and inflexible silos of government funding appropriations. New Zealand's hierarchical and linear accountability as operates now is a significant barrier to service innovation and resources being used efficiently.

IHC is concerned about the impact of recently announced government changes on the well-being of children with an intellectual disability and their families. In particular the requirement for sole parents of disabled children over the age of six to return to work when there may be inadequate supports in place for the disabled child, either in school or in after-school care places. This will be an additional stressor on the parent of a disabled child. Some of the changes being considered by the Welfare Working Group (WWG) if implemented could further compound the difficulties faced by whanau with a child with an intellectual disability. Supporting parents of disabled children into paid work requires well connected, across-agency policy settings, systemic flexibility, appropriate resourcing and responsiveness.

IHC supports the principles suggested by the Children's Commissioner upon how decisions to cease or reduce funding are made and would add a further principle.

- there is a lack of demonstrated capacity to respond to the needs of disabled children and other minority groups of children

Lack of information sharing has been identified as a major barrier to effectively watching out for children. Getting the right kind of support sooner could make changes in monitoring vulnerable children better and improve information sharing practices.

Families told IHC at our Start Strong seminars that little is being done to track disabled children as they move through various agencies after birth and providing data collated across sectors to assist coordination between agencies and to check to see parents have the necessary information and support to make informed decisions. Aside from the advantages to the child with a disability of having a history of being in the system through contact with Well Child/Tamariki Ora services, early education and disability specific agencies there are considerable benefits to planning and resource allocation both across and within sectors. For example, if a primary school knows ahead of time that a certain number of children with disabilities in their catchment area will be turning five in a particular period and has an indication of their likely support needs then the school is able to more effectively prepare and plan.

IHC does not support introduction of mandatory reporting. We believe there are sufficient provisions in the Privacy Act to allow use of discretion when there is imminent harm to a child. Amendment to Privacy Information Sharing Bill 2011 allows breach of privacy principles if a situation is judged to be serious and removes the imminent criteria.

While this may be a useful step IHC recommends that there is an immediate review and reestablishment of the interagency reporting protocols for child abuse management “Breaking the Cycle” developed by the then Children and Young Persons Service in 1996. In addition IHC supports the reintroduction of Community Liaison Social Workers who had the primary role of raising awareness about child abuse in communities to encourage better recognition and response to vulnerable children.

IHC supports the suggestions made by the Children’s Commissioner regarding information sharing between existing and new (enrolments of infants on the NIR with opt off clause) information systems and those protections in place to safeguard against inappropriate accessing and sharing of information.

IHC affirms the need for a child and whanau centred/ life course approach to working effectively and efficiently with children and their whanau. Collaborative, intersectoral approaches promote shared understanding and learning and sharing of resources,

Whanau who attended IHC Start Strong seminars highlighted the difficulties attached to what seems like endless assessments from a variety of disciplines in the absence of practical assistance to address concerns or having to endure long waiting lists.

Common features of successful programmes include a shared values system that puts children at the centre of practice and views whanau as partners, involvement and leadership from senior levels in organisations, working in high trust multi-disciplinary teams, intervening at the earliest possible opportunity before the need for statutory intervention. In addition nationally agreed evidence based tools, and standards, resources, well trained staff with excellent relationships with other sectors are required if New Zealand is to improve outcomes for all children and for vulnerable Maori children with a disability particularly.

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