



IHC Submission

Green Paper for Vulnerable Children

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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 more than 50,000 people with an intellectual disability. IHC has 4500 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 contribute to the discussion on the Green Paper for Vulnerable Children. The Government recognises that New Zealand needs to do better to ensure that every child thrives, belongs and achieves. The Green Paper puts forward ideas on ways to provide better protections and responses for vulnerable children and young people.

IHC notes that feedback from public consultation will inform the development of a White Paper that will outline which of the proposals from the Green Paper will be adopted by government along with a plan for work needed to progress proposals.

While we support this significant process which is aimed at better responding to vulnerable children, IHC is disappointed and concerned that the paper does not recognise to the extent it should, that many disabled children do not thrive, belong or achieve, because of their disability. In addition many other disabled children become vulnerable when their families do not receive early, sustained, and flexible 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 may be 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.

Families with 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 financial or time limits 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 difficulty 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. The disabled child also can develop more extensive relationships of trust with greater numbers of people, 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 some cultures infanticide and "mercy" killings occur because of cultural belief that the child will bring misfortune to the family or community. Sometimes infanticide or killing occurs because of the belief that the child is suffering and would be better off dead.

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 systemic 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. What would be regarded as intolerable if the child was non disabled is ignored because the child has a disability.

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.

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 be reflected in legislation, 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.

IHC believes that many of the recommendations made within the United Nations report would translate well into the New Zealand context and we hope that the White Paper favours this approach.

Families 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 Call to Action: What needs to change for children and young people with disabilities has also informed our feedback on the Green Paper. The Call to Action and Start Strong Action plan are attached to IHC's submission to the Green Paper.

We have divided our comments into two parts. Section three provides an overall response which outlines the context that frames our specific responses in Section four to the proposals made and questions asked in the Green Paper.

The key points in IHCs submission are that many disabled children are 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 when they do not receive early and sustained support which is flexible, timely and integrated and when they are not included in community.

3. Overall Response

IHC is encouraged that the Government has signaled a long term commitment to improve outcomes for vulnerable children. As a country we know a lot already about what contributes to resilience and risk, what works well, what can be built on and what needs to improve. IHC hopes the Green Paper and subsequent work 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 endorses the Green Paper's child-centred focus and emphasis on the importance of early support and intervention for children and their families and caregivers. 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, iwi, hapu and communities. Key areas of leadership, policy and practice are 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 acknowledges 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.

There are significant systemic issues in poorly coordinated policies and service delivery that negatively impact on all children and their families as identified in the The Public Health Advisory Committee (PHAC) Report (2010) - *'The Best Start in Life: Achieving effective action on child health and wellbeing'*. Those from disadvantaged groups are among those most affected by these problems including children with high and complex needs or disabilities.

Successfully addressing these issues for all children and their families will have benefits for children in vulnerable circumstances. The Government justifies 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 is sufficient to bring about the greater integration that is needed and consider that the Action Plan for Children as proposed should encompass specific measures where needed for children in vulnerable circumstances. IHC suggest that an Action Plan for **all** children is required with specific actions for children in vulnerable circumstances.

The Green Paper recognises having a disability and/or significant health problems among risk factors for vulnerability and also speaks of the additional supports that may be needed for parents of children with challenging behaviour or disabilities. IHC is therefore disappointed and concerned at the lack of reference to children with disabilities in the statistics given, suggestions made and questions asked. IHC notes that there is a lack of robust data available on disabled children in New Zealand. This deficit was highlighted in the 2011 report *The Health of Children and Young People with Chronic Conditions and Disabilities in New Zealand*.

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, but disabled children may suffer greater vulnerabilities when they live in violent households, are abused or neglected and live in poverty.

The following themes inform our responses in section four to the suggestions made and questions asked in the Green Paper and are underpinned by New Zealand's obligations under the Treaty of Waitangi and as a signatory to the United Nations Convention on the Rights of the Child (UNCROC), United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

3.1 Children are valuable in themselves

Children with disabilities should be valued as children first with their rights respected and responded to on an equal basis as non disabled children. 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. Extreme examples of the devaluing of disabled children's lives to the point their lives could be taken were seen in media and public reactions 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 to bear, not on the rights of the disabled child to survival and their lives to be valued regardless of their being disabled.

The following example illustrates an extreme case of the statutory child protection agency Child, Youth and Family (CYF) valuing and treating disabled children differently than non disabled children, giving advice that would not be given to the parent of a non disabled child and seeing care and protection issues differently for disabled children.

A mother abandoned her 3 year old child in respite care on the advice of CYF who told her that she didn't have to care for him because of his disability and

that she should just leave him. She did as she was told. He was finally placed several hundred kilometres from home and did not see his mother again for several months. CYF insisted there was no care or protection issue.

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 families cannot look after their children when they have severe disabilities and endorses some views held that families should not be expected to look after their children with disabilities.

Paradoxically 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.

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 fits all” way of seeing the world.

This lack of understanding seems to extend beyond the general public to many of the professionals working with these children. At times it is difficult to obtain specialist input to assist with managing children’s challenging behaviour. This difficulty severely hampers a parent’s ability to care for their child at home and agency response to provide either respite or full time alternative care within the community. Lack of, or inadequate support at this stage can result in an escalation of difficulties that result in crisis and may trigger out of home placement.

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. It is noted however that sometimes community placements provide an institutionalised setting while some staffed residences provide a family-like setting. 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 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.

3.2 Children in vulnerable circumstances

There is no simple answer to the question as to which children constitute the population of vulnerable children. The Green Paper acknowledges the difficulties in measuring and describing vulnerability, with vulnerability often the result of an accumulation of factors which can change as a child grows up.

Children may move in and out of vulnerability. Two periods are identified where children are especially vulnerable: when they are very young and when they enter adolescence. The Green Paper focuses on those children represented in the statistics for CYF cases of abuse and neglect, students truant from school, hospital admissions that could have been avoided or result of assault, neglect or maltreatment, or living in households where domestic violence occurs. Two New Zealand longitudinal studies on child development and wellbeing estimate that approximately 15% of children are vulnerable or live in vulnerable circumstances.

The Green Paper discussion acknowledges that while individual factors do not necessarily cause a poor outcome they can work together to increase the level of vulnerability. 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. The negative impact on well being is compounded when children and their families are not connected to social and cultural supports or their communities. 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 outlined above. 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 families. Parents with limited social and community support may be 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. Lack of respite or breaks in child care responsibilities can contribute to increased risk of abuse and neglect.

Families who attended IHC's Start Strong seminars spoke about the difficulties they had accessing information about government funded entitlements and support and assistance available within their community.

These difficulties compound when families feel not welcomed and treated as 'other' by universal/mainstream services. Families talked about the sense of isolation which comes from having a child with a disability. Clearly isolation can increase risk to children because there are fewer "eyes" monitoring their safety and well being.

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. As referred to in the previous section disabled children can be treated differently than non disabled children. IHC has many case examples which evidence not only a lack of communication between agencies, but more costly care options being put in place.

Zachary is 13 and was suspended from school when he was just 11 years old. He lived in a locked environment in his parent's home and they received regular respite and home support. He was home schooled. The family were stressed as a result of the intensive support required to care for their child. They refused more assistance than they were receiving over a number of years.

An incident occurred where it is thought that the child may have been harmed by the family. Statutory agencies became involved but refused to take any legal protective action on the grounds that there were no care and protection issues, despite the parents' statements that they would harm the child. Eventually the child was placed in an emergency mental health forensic unit where he was considered to be inappropriately placed. The agency agreed to develop a specialised respite service in the local community. Specialist advice concluded, along with agency staff, that Zachary could over time be placed back at a local school and that he could live in a foster home in the community after a few months with specialist team support.

A proposal to this effect was submitted to CYF although they were advised that it was unlikely that the agency would agree to enter into a section 141 agreement in light of the parents' unwillingness to engage. The cost of the one to one service was cheaper than the other residential and out of community option on the table. CYF were still insisting this was not a care and protection issue. While agency staff waited for approval to provide the one to one service, the MOH agreed to fund a section 141 agreement for the parents to pass custody to the residential provider. Zachary was moved out of his home community into a residential service. It is not clear whether CYF and MOH ever communicated about this or whether the MOH were even aware that there was a proposal for a placement in the local community.

3.3 All families need support

All families need support at times whether informal or formal.

Having information is a first step but getting early supports in place are often extremely difficult and time consuming processes for families. Armed with knowledge about the benefits of early support parents sometimes find that they may not be able to obtain the necessary services or access 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 families identified the need for greater responsiveness, flexibility and coordination than that which they frequently experienced. Typically families have to repeatedly tell their child and family's story and give the same information to access a range of services. Families 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 family. Too often the services that are obtained are fragmented and families 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.

Families 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.

As part of achieving children with disabilities being included in the community of all children they and their families need to be welcomed and appropriately responded to by Well Child/Tamariki Ora services and early childhood care and education providers. This was not always the experience of families who participated in the seminars and a number of parents' spoke of having to continually fight for their child's inclusion or receiving inadequate medical care. Families also want those services to be respectful of cultural differences and diversity with culturally competent practices.

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. 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 family and working in partnership to facilitate co-ordination and planning and delivery of supports. Local area coordinators as proposed in the MOH '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 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.

The following case example illustrates what can happen to families when the wrong support was put in place.

Joe has Down Syndrome and autism. He has severe communication difficulties and becomes aggressive when he is frustrated. Joe used to go to a respite care home placement every third weekend but as his behaviour became more difficult to manage his parents asked if they could have Joe in respite care every weekend and they would care for him during the week. The community agency were agreeable to this but felt for the safety of other children in the home, extra funding was needed for additional staff support. CYF were involved and referred Joe and his family to the High and Complex Needs team. The community agency providing the respite care was asked to put in a respite service proposal for the extra care which they did. The mother was told that she had to put her child in full time residential care in order for a one to one service to be able to be funded. Despite the weekend respite option being a fraction of the cost of the full time residential service the mother signed a full time out of home agreement under section 141. She did not want her son in full time out of home care but agreed to this as she was informed that she could not get the respite option Joe needed. She remains most unhappy about Joe being out of her full time care well before she was ready for this to happen

3.4 Context that is supportive of child and family well-being

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 (28th 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 in where better use could be made of existing resources as well as areas that require greater investment. More detail is given in specific responses in Section 4.

The following case example shows how the lack of understanding by agencies and community, and the lack of specialist resource can lead to increase the aggression of children and their “unmanageability”.

John has an intellectual disability as a result of a chromosomal abnormality. There are other side effects such as depression, affective schizophrenic disorder, aggression.

John was receiving respite in a respite facility however because of his behaviour. Respite services had been suspended pending the agency getting some support from the Behaviour Support Agency to manage his behaviour and a meeting of involved health professionals. John was being very aggressive and while he had not caused serious harm, there was a possibility he could physically harm other children receiving respite and the respite agency staff. Staff cannot anticipate when John will hit out. Hitting and throwing things was frequent and unable to be anticipated.

John was unable to access the Behaviour Support agency in the area because the NASC would not refer him – even if they had referred him the local Behaviour Support agency was overloaded and could not take his case.

The health professionals meeting could not assist and while confirming that John's brain tumours were not causing the behaviour, they were unable to offer any help beyond insisting the agency accepted John back into respite

For several weeks the family had received no respite. The agency sought an emergency brief intervention from the agency Behaviour Support Team to assist with service design and to look at the situation. Prior to Christmas in desperation the family pleaded for help and the agency responded with emergency respite because the family was experiencing extreme stress. A Behaviour Support Team specialist provided a report that suggested some practical strategies as to how the respite service could better provide for John's needs. The respite centre was re-arranged and the schedule adjusted to better meet John's needs. The Behaviour Support team provided two days training to respite staff, family and other agencies such as the school who worked with John, so that a consistent approach could be adopted.

On the first night of respite with the new actions and arrangements as recommended there were no incidents of aggression.

3.5 Achieving better integration and collaboration

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 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.

Julie's story illustrates professionals not working in a collaborative manner and ignoring the views of those who know the child best.

Julie was living in a foster family arranged through CYF. Her foster parents have taken legal orders. She has an intellectual disability and autism. Julie is often physically restrained by her foster parents as they said she self-harms.

Julie has been staying recently at a respite care home. The respite agency staff reported that Julie was settled in the home, quite easy to manage, and that she was beginning to communicate with them more. Her birth family live nearby and are trying to have ongoing contact with their child. Previous care and protection issues no longer exist, although Julie's mother would require support to care for her.

CYF proposed to place Julie under a section 141 agreement and send her to a residential service in another city. The Needs Assessment and Service Coordination Organisation (NASC) state that a placement for Julie in an out of community placement under a section 141 agreement would only be acceptable if there are no options available in the community.

At the Family Group Conference (FGC) the participants (including the NASC) are advised of a possible foster placement in the local area with a very experienced caregiver. But, the manager of the proposed residential placement in another city tells the FGC that unless they agree straight away he will not consider taking the child and that they may then be left without a placement. The agreement is signed at the FGC. The MOH were not advised by the NASC that there is a possible foster placement within the local community.

The allegations of abuse of Julie when respite agency staff found extensive bruising on Julie after she came to respite were investigated by CYF who concluded that no abuse had occurred and that the bruises were a result of self-harm. In the view of the respite agency staff Julie could not have bruised herself in the places where bruises were noted

The evening after the FGC the respite agency that has been looking after Julie for several weeks and who have watched her thrive and become settled, are phoned and told to have Julie ready by early the next morning to leave for her catch a plane to the new residential service. The residential service staff and Julies' foster parent arrive and give Julie sedatives to calm her for the journey. She has no opportunity to say goodbye to her own family, her siblings or fellow pupils. Her foster parent of several years flies to the new residential service with her and is back home by midday. Counsel for Child who was at the FGC and had supported Julie's placement in the community to the agency when she was seeking emergency respite said nothing in the FGC. The psychiatrist involved with the child clearly indicated that she thought Julie required the specialised care of a residence because of her difficult behaviour, despite the respite agency confirming that Julie was not difficult to care for and had responded well, particularly when restraints were removed.

4. Specific responses

In this section feedback is given on the suggestions made and questions asked in the Green Paper. Issues of concern for disabled children and their families are highlighted along with actions sought. In addition we have profiled some examples of services and programmes that demonstrate features of good practice. We have grouped our responses using the headings in the Green Paper - share responsibility, show leadership, make child-centred policy changes, and make child-centred practice changes.

IHC endorses the recommendations for change contained within the submission from the Children's Commissioner and particularly support the seven identified goals and alignment with the United Nations Convention on the Rights of the Child.

We will not repeat those points well made by the Commissioner. This section of the IHC submission is intentionally brief. We offer for your consideration two diagrams (figures 1 and 2) which outline a public health approach to supporting families and responding to vulnerable children. Both diagrams feature a strong base of access to universal formal and informal supports and provision for targeted assistance when required or necessary.

4.1 Share responsibility

IHC concurs with the Children's Commissioner's view that the Children, Young Persons and their Families Act, 1989 provides a sound legislative platform for balancing the roles of family and whanau and children. We are however of the strong view that 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 moving into out of home and often out of community placements with no legal representation or statutory oversight. It is estimated 10-20% of children and young people in care are disabled. 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 Department of Child, Youth and Family. 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 families or communities.

Families have told IHC that mainstream children's agencies in communities are not always responsive to disabled 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.

As acknowledged in the Green Paper disabled parents with disabilities face some additional hurdles. This is even more so when one or both parents have an intellectual disability (Mirfin-Veitch, 2010). There is a greater risk of out of home placement for those children. Parents who have an intellectual disability need extra and long term support in order to be adequate parents. Without such support the health and wellbeing of their children may be at risk in terms of experiencing neglect or abuse.

The assumption typically made is that parents with an intellectual disability are automatically and forever inadequate as parents. This can result in discriminatory treatment by the law and government agencies, lack of support to parents by generic and/or disability support services and inadequate efforts to maintain contact with parents when children are placed away from their birth family.

IHC supports the Children's Commissioner's positions 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.

The following initiatives were profiled at IHC's Start Strong seminars are examples of agencies sharing responsibility to reduce vulnerability for children and build capacity in families.

Community Living Trust and CYF – agencies working in partnership (Waikato)

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 Community Living Trust and CYF has reduced the need for CYF to take status for referred families. The disability liaison professional working in the Community Living Trust 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

Right Service Right Time (RSRT) - Christchurch

Right Services Right Time – to get right service, at right time (quick response) and enhance collaboration, multi sectoral, multiagency – anyone can refer, referrals go to most appropriate agency. Range from information and advice, brief intervention; consult assessment, referral to single agency, Strengthening Families, CYF statutory intervention

Findings from evaluation (Quin, 2012)

- 100% of families agreed RSRT helped connect them with the service they needed
- 88% of families said they started receiving services promptly
- 88% of families said the support they received was helpful
- 75% of families said their wellbeing had improved as a result of the support they received
- 84% of service partners, stakeholders and panel member respondents identified that RSRT had increased effectiveness due to sector wide collaboration Increased effectiveness 88%

Key to initiatives success:

- Agencies entering into a formal agreement to provide one identified entry point to a wide range of supportive social services
- Good ‘buy in’ with mechanisms put in place to facilitate information sharing between agencies and a collaborative and coordinated approach to service provision
- Trusting relationship
- Clearly defined expectations around response times and ability to fund certain types of responses increased the organisation’s ability to respond appropriately.

4.2 Show leadership

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 positions of the Children’s Commissioner on working with whanau, hapu, iwi and Maori and Pasifika leaders.

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.

4.3 Make child-centred policy changes

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.

Targeted and universal services

IHC supports the provision of universal services but balanced with services of varying intensity matched to different populations of need. Clearly funding emphasis must also 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 inefficient use of resources and a poor return in investment. For some children and their families 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 family that will necessitate more complex and costly interventions 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 may have to operate within multiple sectors and the current and inflexible silos of government funding appropriations. New Zealand's hierarchical and linear accountability as currently operates is a barrier to innovation and more efficient use of resources.

The IHC Start Strong seminars profiled some good examples of innovative practice in working with disabled children and their families which are difficult to sustain because of inflexible contracting arrangements and silo disputes.

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 includes 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
- Our role in systems navigation, opening gates
- Future planning

IDEA Specialist Services, Communication and Behaviour Service

This is a proactive service that provides early behaviour and communication support to children and young people with Autism Spectrum Disorder (ASD). The small team of highly qualified staff provide advice and tools to work with referred children and their families and alongside other services across a range of settings – home, school, health and in community. Providing early assistance reduces the likelihood of the child getting frustrated anxious or angry and behaviour problems escalating. Critical to the success of the service are skilled staff who are experienced in working with families and children with ASD.

Peter is a 6 yr old boy with ASD who was referred because of concerns about his lack of social skills and engagement with peers. He was also being teased at school. The intervention included a social skills programme using drama with peers (across settings i.e. home and school) to promote emotional and imaginative development; such as turn taking, waiting, acknowledging others, pretend play, adding ideas to play and negotiating change. The outcomes for Peter were being able to cope when it was someone else's turn and showing an increase in stress tolerance. Peter is now invited to peer's birthday parties and has regular play dates.

He engages in reciprocal play with his siblings and is more accepting of change. His parents and the school have learnt strategies that can continue to be used and built on.

While this service specifically works with children and young people with ASD, the principles of early and proactive communication and behaviour support should be implemented in supports for all disabled children.

IHC is concerned about the impact of recent 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 are inadequate supports in place for that 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 families 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.

Where should funding be taken from?

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

Watching out for vulnerable children: Information gathering and sharing

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.

The lack of information on children with disabilities provided in the background papers that was noted in Section 3 is reflective of a wider issue concerning a dearth of available integrated data on children with disabilities and their families and baseline information against which to measure improvements, quality and outcomes.

No one is tracking 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.

4.4 Make Child-centred practice changes

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

Common features of successful programmes include a shared values system that puts children at centre of practice and views families 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 children particularly.

The following example illustrates child centred practice;

IDEA Specialist Services - ASD Plus: Education for Families

An independent evaluation (Litmus 2011) described ASD Plus as “a high quality programme, developed from a national and international evidence base and in line with the NZ ASD Guideline” and found the tailored, individual approach offered by ASD Plus to be a real strength of the programme. Families valued the benefits they derived from participation in the programme and the opportunity to work in partnership with IDEA Services to determine both mode of delivery, and specific goals the family wishes to achieve. The options of families group sessions with a small number of other families, individualised sessions for a particular family or whanau group, distance learning via internet, DVD, reading material with phone/email/face to face contact offer flexibility that is responsive to what suits families in delivery to suit what works best and is responsive to cultural, language and locality needs. While this parent education programme is aimed at families with a child (0-5 years) who have ASD it provides a

good template for effective delivery of parent, family and whanau education that could be extended to other groups.

Key findings of the evaluation were that after completing the ASD Plus programme:

- 80% of families felt they better understood how ASD affected their child's learning
- 90% of families said they better understood their child's behaviour
- 80% of families reported they had learned to adapt their own communication to suit the needs of their child
- Other reported benefits were that children showed improved communication and less problem behaviours, families felt more in control and had calmer, more relaxed households

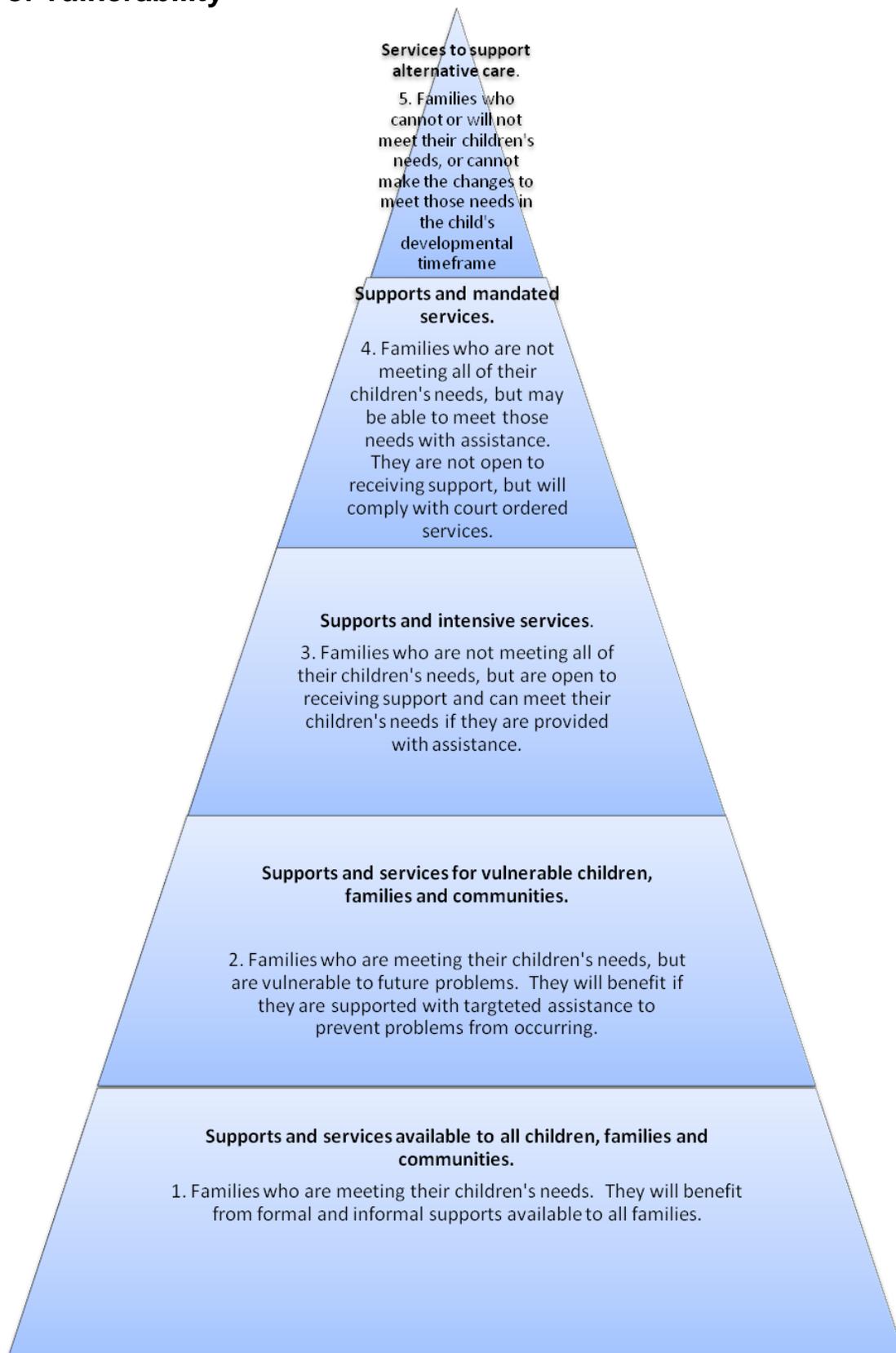
The service gathers family feedback and tracks outcomes using the ASD parent outcome questionnaires. These continue to show a high level of satisfaction with both the quality of the programme and skills of the team who deliver it. Recent data shows a 20% gain in skills/coping strategies immediately post the ASD Plus programme. Furthermore, not only are these maintained, but there is continued improvement to 30% at the 6 month follow up point.

Better connecting vulnerable children to services

Families 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.

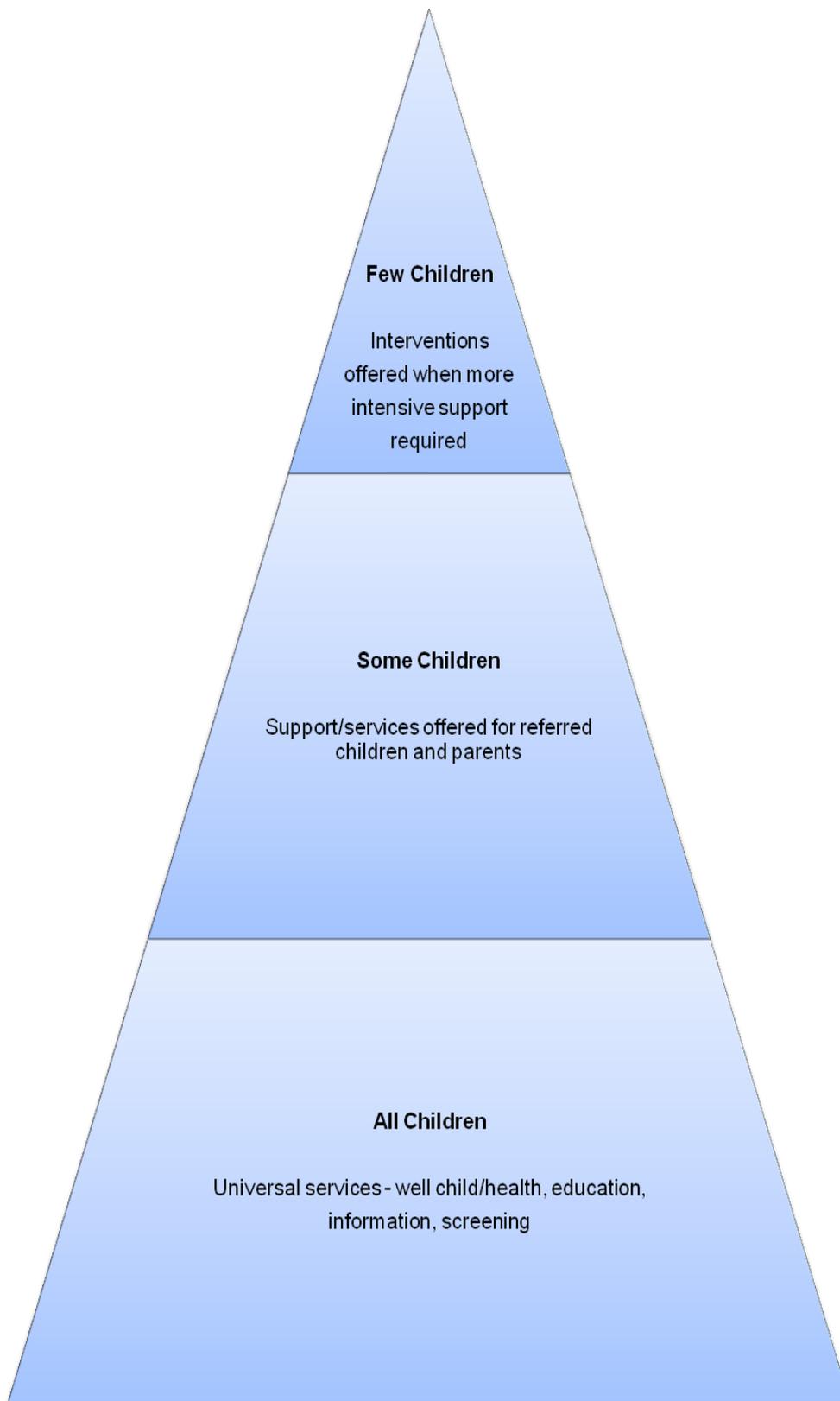
IHC supports schools and ECE centres being better used as sites for the delivery

Figure 1: Services and supports matched to different populations of vulnerability



From Bromfield Bromfield, L. *Minimising cumulative harm for vulnerable children: Does the Green Paper reflect international best practice?* Paper prepared for Social Service Providers Association Aotearoa Inc. December 2011.

Figure 2: Supports/services for children with disabilities and their families: A tiered approach



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