

## **A Rights gap for children with disability**

### **Introduction**

Today I am going to talk to you about a group of children and young people with intellectual and/or physical disabilities between the ages of birth and 17 years. This group of children and young people are defined as being “severely disabled”. They cannot live with their family/whanau or family group and their “severe disability” is considered to be the reason. They are a small group of approximately sixty children and young people at the present time.

The law for the care or protection of children and young persons in New Zealand, the Children Young Persons and their Families Act (CYP&F Act), was enacted in November 1989. At the time it was enacted it was recognised internationally as an extremely innovative piece of legislation.

There were a number of radical differences to the legislation it replaced. The most significant differences that relate to the care and protection of children and young persons were:

- the recognition given to the role and responsibilities of the family/whanau, hapu, iwi and family group in caring for, and making decisions for their children and young people ;
- the provision of a set of principles that were to be applied by any organisation or person carrying out responsibilities under the Act;
- a statutory Family Group Conference that had to be convened when children and young people were considered to be in need of care or protection;
- a distinction between children and young people requiring care and those requiring care or protection; and
- separate provisions that relate to children and young people with disabilities,- including those children and young persons who were considered to be so mentally and physically disabled that suitable care could only be provided for them in the care of an organisation or body approved by Child Youth and Family and the Ministry of Health

These separate provisions also included children and young persons with physical and mental disabilities not considered to be so severe, however today I am only going to talk about how these legislative provisions are applied for children and young persons with “severe disabilities”, as my previous research and experience of the practical application of the legislative provisions has specifically focused on children and young people with “severe” mental and physical disabilities. The law as it relates to those with “severe” disabilities applies equally to those in the “non-severe” category however.

For the remainder of this presentation, for the sake of brevity, I am going to use the term “children” to refer to children and young people up to the age of 17 years. I am also going to use the term “family/whanau” to include “family group”. I use the term “severely disabled children” as it is used in the legal provisions for children with disabilities who require care outside of their family. I will discuss the practical implications for children with intellectual disabilities of a legislative framework that treats them differently from other children and young people. This can, and frequently does, lead to negative operational outcomes that could be avoided were these fundamental rights adequately protected.

### **Why I am interested in this issue?**

After a number of years working as a child protection social worker with the then Department of Social Welfare (now known as Child Youth and Family), I worked as a Care and Protection Coordinator from November 1989 to 1992 – I therefore have a working knowledge of the previous and existing legislation. From 1992 to 1999, I worked as a Senior Policy Advisor in the operations division of the Child Youth and Family (CYF) national office. In these capacities I was involved in both the implementation and the development of operational policy in relation to the enactment of the new legislation. I became aware at that time of what I saw as a number of contradictions in the legislative provisions for children with disabilities.

In 2001, I was contracted by IHC, the Department of Child Youth and Family and the Health Funding Authority to complete a review of children and young persons in IHC care. This file-based research further highlighted the often the negative operational outcomes for disabled children who came into out of home care under these separate provisions of the Act.

Since 2005, in the course of my employment as a Regional Service Manager for IDEA Services, the service arm of IHC, I have been the recipient of a number of referrals from CYF and the Ministry of Health for children with disabilities requiring out of home care. I have become increasingly concerned about the way in which these provisions are being applied, the interagency disputes, the disputes between government departments about funding responsibilities and more critically, the lack of legal protection for these children.

In 2005, I was involved in drafting the IHC written submission to the Social Services Select Committee on the Children Young Persons and their Families Bill (no 6), prepared by our IHC Advocacy Team and was one of the team who presented the oral submission to that Committee. Other agencies working with these provisions also made submissions on the sections of the Bill relating to disabilities. Our submission for the repeal of these provisions was not successful.

I am particularly concerned that the provisions of the Act, as they stand, deny the rights of children with disabilities and fail to provide them with the legal protection afforded to other children who are no longer cared for by their families.

### **What the legislation actually says**

The Children Young Persons and their Families Act (CYP&F Act) contains separate provisions for children who are considered to be in need of a period of extended care outside of their family and those who are considered to be in need of care or protection.

Sections 140 to 149 of the CYP&F Act apply to children where a parent, with the care of the child, agrees to enter into an extended care agreement. The effect of this is that the parent passes the custody of their child (the day-to-day care) over to the care of CYF or an approved agency. They do not pass over the guardianship – that is their responsibility to make decisions about the child. A Family Group Conference (FGC) must be held before any such care agreement can be entered into. This means that the child’s family group must be involved in the decision making and approve the making of the agreement.

Under section 140, care agreements can only be entered into if the parent or guardian usually having the care of the child intends to resume the care of the child at the end of the agreement. Any child over the age of 12 must consent in writing to that agreement, unless by reason of their disability they cannot understand the making of the agreement. The child’s wishes must be given due consideration. The agreements are limited – in the case of a child under the age of seven years to a maximum of six months and for a child over seven years to a maximum of 12 months. Such an agreement could, of course, also be entered into for a child with a disability.

This section relating to care agreements recognises the importance of the agreement of the family group to their child being placed out of their family into the care of an organisation. The limits on the age of the child and the length of time that the child can remain under a “voluntary” extended care agreement suggests that children should not be cared for out of their family under such agreements for long periods and that a “voluntary” extended care agreement is only appropriate when the intention is for the out-of-family care situation to be temporary and for the child to be returned to their parent – that is, it recognises the temporary nature of the situation.

If the child remains out of the care of family for over the specified period and cannot be returned, then the matter will need to be taken to the Family Court through the care and protection provisions of the Act. In any court proceeding under the CYP&F Act, a lawyer will be appointed to represent the child. It can therefore be inferred that the provisions of the Act are set up to prevent children being placed for long periods of time outside of the

care of their family, unless a legal order is made, thus seeking the agreement and oversight of an independent judiciary and legal counsel.

Given the nature of these restrictions, (the age limitations on the time period a child can remain out of the care of their family which ensures that any such care agreements will be temporary, and the requirement for the child to return to their family at the end of the agreement,) it is with puzzlement that we move to the care agreements for the extended care of severely disabled children.

Section 141 of the Act contains provisions for extended care agreements for severely children who are “so mentally or physically disabled “that care can only be provided for them in the care of an organisation or body approved to provide such care (an agency approved by the MOH and CYF). An extended care agreement made under section 142 of the Act refers to children who meet the definition of a person under the Disabled Persons Act and provides for such children to be placed with a residential care operator. There are currently 43 children in NZ in care under section 141 care agreements, with several children still in the process of MOH approval for them to enter into out-of-family care; and nine children in extended care under section 142 care agreements. Informal discussions with staff from MOH and CYF indicate that children are entering care under section 142 care agreements so that they can be placed in adult residential placements, because of a lack of placement options in the community.

Like the section 140 agreements, section 141 and section 142 extended care agreements have restrictions. Section 142 provides for a “disabled child” to be placed with a residential care operator. A further restriction means that such an agreement can only be entered into for one year, in each instance. An FGC can approve the continued making of such an agreement each year. Such an agreement must have the written consent of a child over the age of 12 years unless they are unable, by virtue of their disability, to understand the nature of the agreement and their wishes (wherever possible) must be ascertained and given due consideration in concluding the terms of the agreement. There is no legal representative or person nominated to ascertain their wishes.

This requirement to obtain the child’s consent and consideration of their wishes applies to children in care under both sections 141 and section 142. In the case of severely disabled children, an FGC is able to approve the making of an extended care agreement for up to two years. This can then be extended indefinitely if an FGC approves the extension. Under amendments made in 2008, these agreements are now reviewed every 12 months.

There are no restrictions on the making of these agreements if the child is unable to return home, under either a section 141 or section 142 extended care agreement and no time limits on the making of an extended care agreement, such as the limitations placed in care agreements under section 140.

Essentially, the legislation provides tight restrictions on organisations entering into extended care agreements for children, without disabilities, requiring care out of their family and restricts the period of time that this can occur, (6 months for those under 7 years and 12 months for those over 7 years and under 17 years).

The question then becomes – why is this protection afforded to children without disabilities under care agreements not extended to those “severely disabled” children with mental and physical disabilities. Intuitively one would suppose that such children would need “more” rather than “less” protection and indeed international law and the international obligations that New Zealand has entered into, reinforce such an intuition.

### **Why were separate provisions for children and young persons with disabilities put into the CYP&F Act?**

The separate provisions in the CYP&F Act were included as a response to the issue of children with disabilities being excluded from receiving services under the previous Act. Before 1989 children with disabilities were usually placed in care without any protection under the law, even though the provisions relating to other children also applied to them as “children first”. It is indeed ironic that the separate legal provisions intended to ensure the inclusion of children with disabilities when they had to be cared for outside of their family continues to exclude them from the legal protections enjoyed by children without disabilities.

At a national meeting of newly appointed Care and Protection Coordinators in Porirua in 1990, ten months after the CYP&F Act had been enacted, the chief legal advisor to CYF was invited to discuss, among other things, the intention and implementation of this section of the Act for disabled children. At that time there had been no FGCs for children with disabilities and the majority of these children in out of home care continued to have no care agreements or court orders to support their placement. The general view of those present, and the reason they gave for not convening FGCs for children with disabilities, was that they believed that parents of children with disabilities should not be required to have their extended family involved in an FGC to discuss the placement of their child outside the family. This was eventually corrected over the next few years.

A lawyer who drafted the legislation recalls that the inclusion of these sections for children with disabilities also intended to provide for a “no blame” situation for parents when they were no longer able to care for their children. While he acknowledged that the general provisions of the child protection legislation were not intended to place blame on any parent who could not care for their child, he suggested that this was not the case in practice. Frequently the debates between agencies and government departments about taking children with disability into care focus on the undesirability of legal action, rather than seeing legal action as providing a fundamental protection for children when they are living out of their family.

Section 14 of the CYP&F Act provides a number of definitions for when a child could be considered to be in need of care or protection. One of these definitions includes situations where a parent is unwilling or unable to

care for a child. This definition applies equally to children with disabilities and is usually invoked in situations where parents are unable to care for their child for periods exceeding 12 months. There is also a provision in the legislation that enable a parent to jointly approach the court with a social worker to apply for legal custody orders for their child. This provision has been rarely used over the past 22 years.

Legislation is usually a reflection of societal attitudes. While it is clear that these separate sections were included with the best of intentions for children with disabilities, I believe that their inclusion reflects an ongoing and historical attitude to the issue of care for disabled children.

Since the early 1900s in New Zealand, parents with newborns with disabilities were actively encouraged to give their child up and place them in institutions outside of their community. In some instances parents were discouraged from seeing their newborn child. If the parent kept their child at home, there were few or no services.

From 1911 the Mental Defectives Act created seven classes of “mental defective”. All those classified as mentally defective were to live in institutions from the age of five. The focus of the Act was on the plight of parents and families caring for such individuals and it was considered that family suffering could be avoided by placing such children in institutional care. While such attitudes can be seen with the benefit of hindsight to be draconian in the least, it is regrettable that 100 years on, similar attitudes continue.

The Burns report by Sir Charles Burn in 1959 highlighted that 17 percent of first admissions to institutions between 1953 and 1956 were children under five and that only 10 percent of these were in the severest category. He argued that separation from family life at such a young age often retarded intellectual development as they lacked the stimulation of family life. Throughout the 1960s the government continued to argue that the best way to help people with an intellectual disability was to improve and expand the institutions and discourage parents from keeping such children at home.

### **So what is the issue and what is the size of the problem?**

The best estimate at this point in time is that there are approximately 43 children in New Zealand who are in care of organisations under section 141 extended care agreements and nine under section 142 extended agreements.

As there is no working definition of a “severely” disabled child and there is no case law relating to this threshold, these provisions potentially apply to all children with an intellectual or physical disability, depending on the interpretation of this term by individuals who often lack experience of children with disabilities. Frequently children with intellectual disabilities whose families are stressed because of any number of reasons will be

display difficult behaviour because of these environmental stressors. Often such behaviour settles once the stress is relieved. Such children are frequently seen to fit the criteria of being “severely disabled”.

Presently there is a move within the Health and Welfare sectors to increase the number of agencies approved to provide care for those children under section 141 extended care agreements. This suggests anticipation by these government departments that there will be an increase in the use of such care agreements in the future, particularly as the Ministry of Health continues to agree that they have the primary responsibility for the care of children with disabilities.

### **So why does this matter?**

National and international legislation recognises that the primary social unit for bringing up children is the family unit. Research and practice has shown that children attain their maximum development potential when they live in families where they can grow and have an opportunity to form psychological attachments to those who care for them. In recognition of the critical importance of children being able to develop a sense of who they are and being able to form stable attachments growing up in their communities and in their families, the law provides protection for those children, who are unable to live with their family group.

Protection for children who cannot be cared for within their family is provided for by ensuring that if those people with the legal responsibility for the care of these children are unable or unwilling to carry out these responsibilities, somebody else will be charged with this duty. Currently when decisions about the extended care of children with disabilities are made, the issue of care and responsibility for those children tends to focus on the severity or existence of the child’s disability, rather than on whether or not they have a parent or guardian who is prepared to exercise their responsibilities. In addition, this decision is made by agencies - that is the Ministry of Health and the Ministry of Social Development, agencies for whom such decisions have funding implications.

Under the CYP&F Act, extended care agreements that apply to all children have time restrictions and conditions of a return home attached, thus recognising that children should only be cared for out of their family for short periods and that a return home must always be the goal at the end of out of home placements. This time limitation and focus on a return home does not apply to children with disabilities.

All children out of the care of their families for more than 12 months must have the legal protection of the judicial system – this includes the services of a legal counsel charged with ensuring the welfare and interests of the child, a 12 monthly (or 6 monthly under age of 7 years) review of their care plan and the oversight of a Family Court judge. This does not apply to these children with disabilities under these care agreements.

In all matters relating to the administration and operation of the CYP&F Act, the welfare and interests of the child shall be the first and paramount consideration (section 6 of the CYP&F Act). Under these provisions for disabled children the focus is on the best interests of the family and their difficulties in caring for a child with a disability, rather than on the interests and welfare of the child.

### **So, where to from here?**

The Select Committee on the Children, Young Persons, and their Families Bill (No 6) declined to repeal these provisions despite strong recommendations from some agencies in the disability sector, opting instead to strengthen the existing provisions to provide for more regular reviews.

If the inclusion of separate provisions for children with disabilities was a response to them being excluded under the previous Act, then 22 years down the track, I would argue that the provisions have achieved their intention. Children with disabilities are no longer placed in long term out of home care without at least an FGC being held, a care agreement being put into place, and a review of the placement by an FGC. However this is not sufficient! Children with disabilities who cannot live within their family must have legal protection like all other children.

While I do not have the time to go through the different obligations New Zealand has to protect and include children with disabilities, it is clear that the existence of these separate provisions are in direct conflict with NZ's obligations under a number of international treaties and conventions. The general care or protection provisions of the CYP&F Act are sufficient for the placement of children with disabilities in out of home care. These separate provisions therefore can be repealed without any further changes to legislation or practice.

The next step in ensuring that the law applies to **all** children who are cared for by organisations outside of their family is to raise awareness of the issue and create a multi-agency ground swell of support to overturn the provisions.

There are barriers to the removal of these provisions. These barriers tend to centre on the debate about whether it is desirable for the Family Court to be involved in matters relating to the need for out of home care for a child whose disability is seen to be a causal factor and the ongoing debate between the Health and Welfare sectors in relation to the funding of such care.

These debates need to be refocused so that the central concern is on the rights of children with disabilities and the extent to which they receive the full protection of judicial oversight when they can no longer live within their families.

Patty Green