

**Our Forgotten Families:  
Issues and challenges faced by parents with a disability in Victoria**



**Parents with a Disability Community Network 2010**



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#### Acknowledgement

Front cover photograph - volunteer models

Written by Kate Fitt for the Parents with a Disability Community Network.

The Parents with a Disability Community Network gratefully acknowledge and thank the many people who contributed to and assisted with the creation of this issues paper.

## Forward

People with a disability, their families, carers and social networks, are finding a new voice. Despite years of transforming the welfare model into one of a person-centred practice provided by client-centred services and systems, there are still constraints on people with a disability which need to be addressed.

Many people choose to welcome a new life into the world and provide that child with love and opportunity. However this basic human right to bear and raise children is not always available to parents with a disability, nor are the supports required readily available.

Throughout the State of Victoria there are pockets of interest and some programs that assist families where a parent has a disability. However, these services are not able to address the whole-of-life issues faced by such families and supports are not adequately funded or available in a timely manner.

We recommend the Victorian State Government takes the lead role in identifying how the implementation of Victorian legislation and policy acts as a barrier for parents with disabilities and their families, and to act to ensure that government, community and the service system can work in a coordinated and collaborative manner to overcome these barriers.

Kate Fitt's report, *Our Forgotten Families: Issues and challenges faced by parents with a disability*, is timely. We support the recommendations made in the report.

Sanjib Roy  
Chief Executive Officer  
Yooralla

Kevin Stone  
Executive Officer  
VALID Inc



*“This report is timely and provides an excellent analysis of the issues facing parents with disabilities, their children, family members, their advocates and service providers. Most telling is the continuing lack of recognition and/ or active denial of the rights of a person with a disability to marry and parent as stated in Article 23 of the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory.*

*How can this ‘lucky’ country continue to treat this growing group of parents in the ways outlined in this Report? As noted in the Background Section there are over 12 legislative and policy initiatives which, in theory, demand equal opportunities for people with a disability in their parenting role. In practice, the equalization of opportunities for parents with disabilities in Victoria (and around Australia) has yet to be realized.*

*Our Forgotten Families: Issues and Challenges Faced by Parents with Disabilities in Victoria is a Call to Action which must be heeded. No one could ignore the powerful arguments that form the basis of the recommendations. No longer can we allow parents with disabilities and their children to languish at the margins of society. The Parents with a Disability Network supported by Yooralla and VALID are to be highly commended for this outstanding report. I commend this Report to you for Action and Implementation”.*

**Professor Gwynnyth Llewellyn (PhD, MEd, BA, Grad Dip ContEd, Dip OT)**

**Dean of the Faculty of Health Sciences, University of Sydney and Director of the Australian Family and Disability Studies Research Collaboration**

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## **EXECUTIVE SUMMARY**

### **Introduction**

This paper provides a summary of the experiences and issues as reported by Victorian parents with disabilities and practitioners associated with the Parents with a Disability Community Network (PWDCN) in 2009.

It is not known how many parents in Australia or Victoria have a disability. It is believed that the number of people with disabilities choosing to take up their right to start a family is increasing [1]. However, the disability system in Australia is reported to be 'broke and broken' [2]; the Child Protection system including the Out-of-Home-Care system is similarly reported to not be coping with increasing demands [3]. With the changing of family roles and structures within the community, universal services such as Maternal and Child Health, hospitals and schools are not in a position to meet the increasing call for these services to better meet the needs of vulnerable families including those where the parent has a disability [4].

Research examining parenting with disabilities reveals that parents with a disability can be good parents [5, 6]. However, there is inadequate Victorian research to examine current systemic responses to parenting with a disability. There is also limited legal and political discourse that defines what constitutes reasonable efforts by the Victorian state and community toward these families. The rights of the child and the rights of the parent as a person with a disability are often presented as contradictory, resulting in inadequate consideration of the Universal Declaration of Human Rights (UDHR) where the 'family' is seen as the 'fundamental group unit of society' (Article 16). The seeming lack of access to resources, supports and funding options often results in practitioners' inability to provide effective or timely responses which compounds the difficulties experienced by many families [1, 5, 7-13]. It is imperative that practical and effective solutions are found and implemented immediately.

### **Context**

Since 1996 Yooralla's Parents with a Disability Community Project, which has established the Parents with a Disability Community Network (PWDCN), has largely focussed on the legal and disability service systems and the effectiveness of support provided to parents with a disability to fulfil their role as parent. In that time there has been the introduction of legislation, policy and programs that should have resulted in positive options and outcomes for parents with a disability and their families. In an effort to gauge the impact of these service system changes the network has collected examples of current experience of parents with a disability in Victoria.

### **Key Issues**

The experiences recorded indicate that in Victoria effort is being made to better support and acknowledge the needs of families where there is a parent with a disability. However, greater effort is required to protect the rights and needs of all family members particularly where a parent has a disability. Rigorous research is also urgently required to examine the Victorian context and to identify future options and strategies to address this matter effectively.

## **Human Rights**

There is inadequate consideration of the issues faced by parents with disabilities and their families under international and Victorian human rights obligations [13].

### **Legal, Disability, Child and Family Systems**

It is reported by parents with a disability that:

- There is a lack of awareness of the issues faced by parents with a disability throughout all systems that engage with persons with disabilities and/or families [14].
- There is a lack of funded, co-ordinated and accessible services for parents with disabilities that accurately reflect the actual needs of families [13].
- They are not considered a priority for Individualised Support Packages.
- There is a lack of funded, co-ordinated, accessible and useable training for parents with disabilities.

## **Advocacy**

Families are not able to access advocacy services (both lay and legal) in a timely manner and from staff who are adequately trained and funded to provide assistance across all services and systems [12].

## **Recommendations**

It is recommended that the Victorian State Government address the following:

### **Human Rights**

#### *Recommendation 1*

Undertake immediate review and establish an annual review process of Legal, Child Protection and Disability Services' processes and practices from a human rights perspective (see page 18).

#### *Recommendation 2*

Ensure that information on Victorian public authorities' ability to meet the human rights of Victorian parents with disabilities and their families is received annually by Government.

#### *Recommendation 3*

Provide resources, including educational programs, to assist parents with disabilities to utilise the Victorian Charter of Human Rights and Responsibilities Act 2006 to better protect uphold their human rights, so that those whose rights may be breached understand how they can be empowered to help themselves.

#### *Recommendation 4*

Undertake awareness raising and educational programs among public authorities so that public authorities providing services to parents with disabilities are educated to ensure that they can deliver services respectful of human rights.

## **Implementing Policy and Legislation**

### *Recommendation 5*

Develop and implement an effective whole-of-government data collecting processes and research initiatives to guide the development of services and funding considerations for parents with a disability and their families.

### *Recommendation 6*

Undertake an immediate review and make appropriate alterations to policies and practices that act as a barrier to parents with disabilities and their families receiving adequate and equitable support from government and community based services. This review should include consideration of:

- The ability of government and the community sector to provide family-focused strength-based and practical support services relevant to the needs of families who often face multiple social barriers and socio-economic disadvantage/s
- The processes and practices of legal, child and family, disability and community based service systems and the manner in which they interact to impede or promote the well-being of the family unit where the parent has a disability
- The ability of government to create services that may act across all service system boundaries to reduce cross over and competition between services and government departments acting to protect limited resources
- The requirement of parents with a disability and their families' need for an urgent response and a priority for individualised support packages based on family rather than individual need
- Strategies, funding and workforce development to strengthen community based services' ability to provide effective support to families to reduce the number of professionals involved in family life, to increase the effectiveness of those services and to reduce automatic referral to tertiary level services of Child Protection.

## **Advocacy**

### *Recommendation 7*

Establish and provide recurrent funding of a specialised advocacy service to better support parents with disabilities and their families throughout the state to access timely and informed advocacy support that adheres to professional standards and ethics.

### *Recommendation 8*

Establish and provide recurrent funding of a specialised service to assist Child Protection, Disability Services and community based services to create information in accessible formats.

*Recommendation 9*

Establish initiatives to work with the courts, government and community agencies to develop clear guidance and protocols in regard to the sharing of information. The aim being to assist parents with disabilities to:

- access advocacy support to achieve equitable opportunities to participate in complaint and review processes
- receive equitable opportunity to consider and respond to the information being collected, recorded and shared within the service and legal systems.

## INTRODUCTION

This paper provides a summary of the experiences and issues as reported by Victorian parents with disabilities and practitioners associated with the Parents with a Disability Community Network (PWDCN). The opinions and experiences of parents with disabilities, their families and practitioners are put forward throughout this paper. They are divided into key areas of Human Rights, Implementing Policy and Legislation and Advocacy. Recommendations to address the issues raised are also put forward.

Throughout this paper the phrase 'parent with a disability' is taken to mean a parent who has an impairment which may be intellectual, psychiatric, physical or sensory in origin. Generally to be considered within this category in Victoria, the impairment must be verified by a professional such as a medical doctor and must impact on the individual's day-to-day functioning. Much of the research referred to in this document centres on parents with an intellectual impairment. However, PWDCN does not wish to convey that parents who have a disability of any type should be responded to in any way that does not reflect the individual's strengths, interests and needs. PWDCN believes that parents with a disability are not a homogenous group.

It is not known how many parents in Australia or Victoria have a disability. It is believed that the number of people with disabilities choosing to take up their right to start a family is increasing [1]. However, the disability system in Australia is reported to be 'broke and broken' [2]; the Child Protection system including the Out-of-Home-Care system is similarly reported to not be coping with increasing demands [3]. With the changing of family roles and structures within the community, universal services such as Maternal and Child Health, hospitals and schools are not in a position to meet the increasing call for these services to better meet the needs of vulnerable families including those where the parent has a disability [4].

Literature shows that:

- Notifications of alleged child maltreatment have tripled in the last ten years and child removal rates have doubled [15].
- An estimated one-in-three cases in Australian children's courts includes a parent with a disability [7, 16].
- The numbers of people with disabilities choosing to become parents is increasing [14, 17].
- It is thought that parents with a disability represent less than 1% of the population [16]
- The rate of child removal for parents with a disability is estimated at between 40% to 60% [1, 5, 8]

However, research examining parenting with disabilities reveals that parents with a disability can be good parents [5, 6] and removal of children based on disability alone is discriminatory and contrary to human rights principles [13]. There is inadequate Victorian research to examine current systemic responses to parenting with a disability. There is also limited legal and political discourse that defines what constitutes reasonable efforts by the Victorian state and community toward these families.

The rights of the child and the rights of the parent as a person with a disability are often presented as contradictory resulting in inadequate consideration of the Universal Declaration of Human Rights (UDHR) where the 'family' is seen as the 'fundamental group unit of society' (Article 16). The lack of access to resources, supports and funding options often results in practitioners' inability to provide effective or timely responses which compounds the difficulties experienced by many families [1, 5, 7-13].

Children in a family that include a parent with a disability are often listed as being vulnerable to neglect or abuse within Child Protection policy [3, 18]. The current inadequate policy and practice response toward these families has resulted in the systemic discrimination or neglect of many of these children [10, 12, 13]. Greater awareness of human rights instruments such as the Victorian Charter of Human Rights and Responsibilities Act 2006 is essential to ensure human rights sensitive practice is implemented at all levels of service planning and delivery and throughout government and community systems.

Throughout 2008 and 2009, the PWDCN held two forums, facilitated network meetings and participated in conversations with parents with a disability, families and practitioners from Community, Child and Family, Disability and Legal services. During these events the experiences of parents with a disability and their supporters were collated and are now presented within this document. It is imperative that practical and effective solutions are implemented immediately to begin to address this serious problem.

## BACKGROUND

*The denial of the right to reproductive freedom takes many forms for women with disabilities – coerced abortions, pressure to undergo tubal ligations and hysterectomies, unlawful sterilisation, systematic denial of appropriate reproductive health care and sexual health screening, limited contraceptive choices, a focus on menstrual control, **poorly managed pregnancy and birth, and the denial of rights to be a parent based solely on the fact of disability** [13].*

Since 1996 Yooralla's Parents with a Disability Community Project, which has established the PWDCN, has largely focussed on the legal and disability service systems and the support provided to parents with a disability to fulfil their role as parent. The aims of the network are to:

- Encourage and empower parents with a disability to be actively involved in directing the project
- Educate the community about the rights of parents with a disability and their needs and issues
- Work with and educate the government and service providers to provide relevant and accessible services to parents with a disability
- Facilitate peer support networks of parents and potential parents who have a disability in Victoria
- Develop an information and resource service for parents with a disability.

In this time a number of political and service system events have occurred, or been strengthened, that should have had a positive impact:

- The *Universal Declaration of Human Rights* – specifically Article 12 and 16
- The *Convention on the Rights of Persons with Disabilities* particularly Articles 23 and 25
- The release of the *A Fairer Victoria policy* which encourages a whole-of-government and community approach to supporting Victorian's most vulnerable citizens
- The introduction of the *Victorian State Disability Plan 2002-2012* and *Disability Act 2006* which saw the adoption of a rights-based and individualised approach within Victoria Disability Services
- The introduction of the *Victorian Charter of Human Rights and Responsibilities Act 2006*
- The creation of *Individualised Support Packages and Individualised Planning* for users of Disability Services
- The introduction of the *Child Protection Every Child Every Chance* policy framework and the *Children, Youth and Families Act 2005*. Which, like the United Nations, recognises the family as the basic unit of society and encourages family services to work collaboratively to adopt a preventative approach to child abuse and neglect
- The development of the *Child First* initiative
- The addition of the conciliation step in Children's Court proceedings

- The development of the *Healthy Start* initiative which undertakes workforce development for services working with parents with intellectual disability
- The development of the *CoPMI* and *FaPMI* projects that undertake workforce development for families who have a parent with a mental health issue
- The development of some specialised services such as the Royal Women's Hospital Women's Individual Needs clinic.

### **How Fair is Victoria? Current issues**

The experiences recorded highlight that in Victoria effort is being made to better support and acknowledge the needs of families. However, greater effort is required to guarantee the rights and needs of all families particularly where a parent has a disability. Current initiatives have not sufficiently assisted many parents with a disability to uphold their right to parent and for their children to be provided with appropriate support so that, '*...every child thrives, learns and grows and is respected and valued to become an effective adult* [19].

It is interesting to note that most issues raised in this paper are similarly raised within current national and international literature [1, 5, 7]. Rigorous research is now urgently required to examine the Victorian context and to indentify future options and strategies.

### **Key Issues**

#### Human Rights

There is inadequate consideration of the issues faced by parents with disabilities and their families under international and Victorian human rights obligations [13].

#### Legal, Disability, Child and Family Systems

- There is a lack of awareness of the issues faced by parents with a disability throughout all systems that engage with persons with disabilities and/or families [14].
- There is a lack of funded, co-ordinated and accessible services for parents with disabilities that accurately reflect the actual needs of families [13].
- It is reported by parents with disabilities that they are not considered a priority for Individualised Support Packages.
- There is a lack of funded, co-ordinated, accessible and useable training for parents with disabilities.

### **Advocacy**

Throughout this paper the term advocate is used to refer to non-legal advocates who assist people with disabilities within the service system. Legal advocates are referred to as legal representatives.

There is a high level of representation of parents with disabilities in the courts and the Child Protection system [12]. However, families are not able to access advocacy services (both lay advocates and legal representatives) in a timely manner and from staff who are adequately trained and funded to provide assistance across all services and systems [12].

## Human Rights: Freedom, Respect, Equality & Dignity

*In 2009, in one of the most enlightened and wealthiest nations in the world, it is possible for persons with disability to die of starvation in specialist disability services, to have life-sustaining medical treatments denied or withdrawn in health services, to be raped or assaulted without any reasonable prospect of these crimes being detected, investigated or prosecuted by the legal system, and to have their children removed by child protection authorities on the prejudiced assumption that disability simply equates with incompetent parenting' [2].*

The *United Nations Convention of the Rights of Persons with Disabilities Article 23* encourages 'respect for home and the family'. Within this article signatories agree to take measures to eliminate discrimination, to provide assistance to parents with disabilities to undertake their child rearing responsibilities and to not separate parents and children on the basis of disability. Australia became a signatory to this convention on 30 March 2007 [20].

The *Victorian Charter of Human Rights and Responsibilities Act 2006* (the Charter) operates to protect a range of human rights including the right to privacy and protection of families and children, among others. The Charter aims to ensure that all Victorian public authorities act compatibly with human rights and must consider human rights within any decision-making process [21]. This means that decision makers need to consider human rights that may be impacted by the implementation of a decision, policy or program. This may sometimes involve assessing a range of competing human rights. For example, addressing the right of families as the fundamental group unit of society to be protected against the right of a child, without discrimination to protection of their best interests.

The Charter provides that its human rights may only be reasonably limited by decisions or actions of public authorities, which must take into account a range of factors including:

- the nature and importance of any human rights potentially breached
- the importance of the purpose of the proposed limitation on human rights
- the nature and extent of the limitation
- the relationship between the limitation and its purpose (whether the limitation is a proportionate response to an issue)
- any less restrictive measures reasonably available to achieve the purpose sought by the limitation.

Although the Charter's rights are based on the rights contained in the *International Covenant on Civil and Political Rights*, a section of the Charter provides that a right or freedom recognised elsewhere (including for example, international law), which is not expressly written in the Charter is not taken to be limited. It is therefore possible to consider the benchmarks upheld in international law and jurisprudence (legal processes and understanding of laws) to enable human rights to be considered more creatively and broadly.

Despite current research many service providers and community members still hold stereotypical and discriminatory beliefs that parents with a disability are a danger to their children and will never be good parents [1, 5, 7, 13, 14].

Parents associated with the PWDCN believe that their basic human rights are still being ignored and that a lack of awareness of human rights issues is still prevalent throughout the community and service systems. Interactions between parents with disabilities and child protective services trigger a range of human rights. These include equality rights (particularly equality before the law, equal protection of the law without discrimination and the right to equal and effective protection against discrimination), the right to privacy, protection of families as the fundamental group unit of society, protection of children's best interests and in some cases, cruel, inhuman or degrading treatment.

Parents believe that the following examples amount to potential breaches of the Victorian Charter of Human Rights and Responsibilities Act 2006. Such parents and their advocates consider that further clarity and definition is required from government and public authorities in regard to these human rights concepts. Parents and advocates also identify a need for resources including educational programs to assist them to utilise the Charter to uphold their human rights, so that those whose rights may be breached understand how they can be empowered to help themselves. Public authorities providing services to parents with disabilities need to be educated to ensure that they can deliver services respectful of human rights.

## **Human Rights: Experiences and Issues reported by Victorian families and supporters**

### **Public Authority Awareness**

*Two parents advised of their inability to attend school events as the school failed to consider accessibility issues when booking the venue for the occasions.*

### **Myths, Attitudes & Reasonable Adjustment of Service Provision**

*One family told of their fear of their neighbours who make constant false complaints to numerous authorities about the family. The neighbours have openly referred to the family as 'freaks' and told the family that they will ensure the family is moved out of the area. It is alleged that these neighbours were successful in removing another mother with a disability from the area. The family concerned does not complain about the neighbours for fear of retribution which in the past has included physical assault.*

*One parent reported that she was notified to Child Protection services because a service provider assumed the parent's disability would encourage her to throw the baby against the wall. While the parent was exonerated in legal proceedings the experience was traumatic.*

*A psychologist, following the completion of a two hour office-based cognitive assessment, wrote a report for court to state that the parent was 'un-teachable and could not look after herself, let alone a child'. This was accepted by the courts as justified reason for the child never to return home. The parent and her supporters felt that the assessment and process:*

- *ignored the parent's strengths as, without assistance, she had managed to learn how to function on a day-to-day basis*
- *ignored best practice advice on the topic of assessment and teaching of parenting skill*
- *failed to consider available supports or strategies to assist in the parenting role or to support the child's right to be supported within the family unit*
- *ignored other possible causes of current difficulties such as trauma, grief and loss.*

### **Equitable Access to Services**

*Several parents advised that Disability Services openly state that parents with a disability are not a priority as they have no obligation to assist a person with a disability to fill the parenting role if the child does not also have a disability.*

*One family reported that the working parent had to leave work and become a full-time carer for his partner and children due to lack of available support for the parent with a disability in the parenting role. The loss of income has resulted in financial issues for the family and they feel they are now 'welfare dependent'.*

*A disability support agency told one parent that if, 'two hours a week of support was inadequate she should place her child in foster care'.*

*One parent advised that once she fell pregnant she was unable to remain at the residential unit. As a result she was forced to reside in a caravan park without supports and without her child once it was born.*

*Two parents provided examples of how their children were removed and placed in care as a result of a lack of appropriate and timely support. While in-home, outreach and personal care services are available to individuals who are not parents they are not always available to assist the individual to fill the role of parent.*

*Advocates report that inadequate attention is given to concepts of the child's right to be supported within the family as the basic unit of society. Advocates felt that perhaps some workers perceive parental disability as too difficult a concept and therefore too difficult to locate support for parents with disabilities as suggested by human rights legislation.*

### **Equitable Access to Resources**

*Several families reported that access to support or aids and equipment is difficult to achieve unless the family is in crisis. They feel it is difficult for families to get help unless the children are at risk of abuse or neglect.*

*One family advised that air conditioning, a vital requirement for those with multiple sclerosis, could only be provided to one room of their rented accommodation. This meant that most family activities had to take place from the parents' bedroom in summer.*

### **Genuine equality before the law and genuinely fair trials**

*Three families advised that the legal process left them feeling like hardened criminals with no emotional or practical support to pick up the pieces and move on after the court process was concluded.*

*Parents identified enormous differences between the facts as presented and accepted by courts and the actual day-to-day reality of life for the family.*

*Two legal representatives advised of the frustration of being in court when a Child Protection worker is not providing 'the most honest' information. Parents report that the evidence of workers is often taken out of context and given greater credibility than the parents' as the systems for presenting evidence favour those who function in a literate and articulate manner.*

*Advocates and services report that families in similar circumstances are treated very differently depending in which region the child lives and who has the most articulate legal representative on court day. For example families commented that some regions such as the North West Metropolitan region have implemented a range of programs and have employed staff in both Child Protection and Disability Services with a 'different attitude'. Families also commented that some staff are working under difficult circumstance and while the staff member makes every effort the outcomes are limited by the resources available to the system.*

*One family reported that Child Protection used attendance at access to state that the family were not committed to their child and therefore the child should not be returned home. However, analysis of the case showed that Child Protection had on 28 occasions made errors or failed to also get the children to access. This highlights how parents with disabilities are scrutinised against standards of which workers with access to resources, vehicles and support staff cannot meet.*

### **Genuine Access to Complaints Processes**

*A legal representative felt that very few parents with disabilities are ever in a financial or emotional position to make complaints in regard to their treatment by court staff and are unable to appeal against decisions, which may be ill-informed and discriminatory, and as such are rarely fought.*

*Complaints about how parents with a disability are treated by Child Protection staff have often either been ignored, or poorly investigated. Requests for reviews of case planning decisions have taken 12 months to complete with Child Protection refusing to provide any support to parents during that time.*

### **Confidentiality**

*Despite never having committed a crime and quite often on the basis of **probable** and not **actual** risk to the child, parents' and families' most private details are scrutinized in court and are subject to court reports. One father reported that at least 15 professionals and his mother in-law had access to the information in the court documents.*

*Many issues surround the use of privacy legislation and information and how it is applied. For example, one parent advised that Child Protection can say and write what they want about her to whomever they want, but threaten people, who she had asked to help, with being in contempt of court if they are given access to information such as court reports to assist her in the case or to make a complaint.*

### **Dignity**

*Parents advised that the process of applying for assistance, of going through assessment and trying to meet eligibility criteria, felt more like begging. 'It was humiliating to have to share your most private details with complete strangers'.*

### **Cruel and Inhumane Treatment**

*Acknowledgement of the trauma and grief created by involvement with the child protection system is not always given. When questioned on the issue, a Child Protection staff member replied that the child, not the parent, is their client; and they have no responsibility toward the parent at all.*

*Three families told of the terror they felt when they were asked to undertake 'yet another assessment'. Supporters advise that there is no research to examine the impact of current Child Protection assessment and monitoring processes on families. They also advise that quite often the requirement for 'extra evidence' would be unnecessary if all Child Protection staff worked collaboratively with other agencies and 'on occasion valued the opinion of someone other than a psychologist who has never stepped foot in the family home'.*

*'They just spent four grand [\$4000] on a psychologist, not to help the family but to do another assessment to tell them what I'd been saying all along. Now they say they don't have the funds to pay to actually do anything real' (Agency worker 2009).*

### **Recommendations - Human Rights**

#### **Recommendation 1**

Undertake immediate review and establish an annual review process of Legal, Child Protection and Disability Services' processes and practices from a human rights perspective.

This should include an examination of:

- equality rights (equality before the law, equal protection of the law without discrimination, and the right to equal and effective protection against discrimination)
- the right to privacy
- protection of families as the fundamental group unit of society
- protection of children's best interests
- cruel, inhumane or degrading treatment.

#### **Recommendation 2**

Ensure that information (a detailed report) on Victorian public authorities' ability to meet the human rights of Victorian parents with disabilities and their families is received annually by Government.

Recommendation 3

Provide resources, including educational programs, to assist parents with disabilities to utilise the Charter of Human Rights and Responsibilities Act 2006 to uphold their human rights, so that those whose rights may be breached understand how they can be empowered to help themselves.

Recommendation 4

Undertake awareness raising and educational programs so that public authorities providing services to parents with disabilities are educated to ensure that they can deliver services respectful of human rights.

## Implementing policy and legislation

*Every piece of policy and legislation will have an impact on the day-to-day life of a citizen—we can only try to make it a positive one (PWDCN participant 2009).*

Parents with a disability are individuals and should not be grouped according to labels placed upon them. It must be remembered that even those with similar diagnosis differ in strengths, interests, personalities and needs [14, 22]. However experience shows that creating a service environment able to meet the individual and group needs of parents with a disability, and their families, can contain many barriers to accessing effective and timely support for the family. These barriers often exist as a result of how policy and legislation is written, understood and implemented [13].

To implement legislation and policy adequately, agencies require a working knowledge of legislation covering the areas of:

- “Disability
- Children and Youth
- Child protection
- Families
- Health and welfare services
- Equal opportunity” [23]

Acquiring this degree of practice knowledge can present an enormous burden on agency time and resources. As pointed out by MacKillop Family Services [24], an organisation working in the area may be required to implement more than 200 different pieces of legislation, policy or guidance. Despite this broad range of legal requirements, there is still much work to be done to ensure that policy enhances life of all families. It would appear from the anecdotal comments on the following pages that the issues that need to be addressed in Victoria also need to be addressed internationally. Tarelton [1] lists these issues as:

- *‘The roles and boundaries of different professionals and services involved with a family and how they can work together (local protocols are an important way forward here)*
- *What level of support should be provided – and by whom*
- *Appropriate and explicit care pathways*
- *Local systems to ensure consistent concepts of parenting are used by the different professionals involved with parents*
- *How support for parenting can be accessed in the absence of a concern around child protection or a child in need*
- *The training required by professionals in children, adult, family support and generic services*
- *Ensuring that generic services, such as [Child First], are informed and equipped to work effectively with parents with learning difficulties*
- *Provision of funding for support services, especially advocacy for parents with learning difficulties involved in child protection and judicial processes*
- *Sharing of examples on how eligibility criteria...operates in practice*
- *Guidance on how families can be supported holistically as children and adult services are reorganised in divergent ways’.*

Tarelton [1] also advises that there is a requirement for reassurance that changes in United Kingdom legislation will not result in more children being removed from parents with a disability. Victoria should also consider this issue in relation to the *Victorian Child, Youth and Families (CYAF) Act (2005)* [25]. Consideration needs to be given to how principles within various pieces of legislation impact on service provision. For example requirements of CYAF act that limit services to those necessary to provide for the safety of the child may not meet the requirements to implement services that are preventative as required of the *Protecting Children: The Next Steps* policy [18, 25]. Disability Services experience similar difficulties where there is lack of clarity in regard to supporting parents with a disability to fill a caring role [13]. Limited access and stringent guidelines surrounding the allocation of Individualised Support Packages from Disability Services does also prevent some families from receiving the support they need to fill the parenting role.

Parents with a disability are listed as being a group at risk of being a vulnerable family within Child Protection policy, within the information on mandatory reporting on the Office of Child Safety Commissioner's website and in the recent Victorian Ombudsman investigation into Child Protection [3, 18, 26]. However, these same parents only rate a passing mention in the *Victorian Disability State Plan* and do not always have access to individualised support packages which may adequately address the urgent and additional support needs that may be required to parent. The current implementation of legislation such as the CYAF Act, in many cases, may reinforce the cycle of deviancy referred to in best practice literature [14].

Clarity is required in regard to the interpretation of the principles of the *Disability Act 2006* and how the legislation does or does not support the implementation of services or supports to assist an individual with a disability to fill the valued role of parent.

## **Implementing Policy and Legislation: Experiences and Issues reported by Victorian families and supporters**

### **Building on current success**

*Parents, advocates and services report of the implementation of a number of positive and practical initiatives aimed to better support parents with disabilities. Services report positively of the **Healthy Start network** where service providers are able to access networks, research, and training. Parents report positively of practical options and resources such as the **Child First program** and the extension of in-home child care services to provide greater levels of in-home parenting support. One family spoke of the childcare as the most logical, practical and flexible service they had ever accessed. Other initiatives include the establishment of specific parenting programs, support groups and mentor programs.*

*These services are not sufficiently funded and service system gaps remain; particularly across geographical locations and between the universal, secondary and tertiary service systems.*

### **Access to community based resources and services**

*Some parents, particularly those with physical disabilities, suffer in silence. They feel they are forgotten.*

*Parents with physical disabilities advise that:*

- *attendant carers are rarely able to provide physical assistance to support the parenting role due to funding and insurance constraints*
- *aids and equipment to assist in the parenting role are often difficult to locate and expensive*
- *family support organisations had little understanding of disability issues or approaches. One worker advised that a service provided equipment to assist with breast feeding but forgot to order the strap, rendering the equipment dangerous to the child.*

*Two families advised of personal and family breakdown where a partner without a disability has been unable to access support to fill employment, carer, parenting and household management responsibilities.*

*All staff and families associated with the PWDCN report of service options being heavily restricted by funding constraints, eligibility criteria and large waiting lists. This frustration was focussed toward case management services and Child First.*

## **Whole-of-government response**

**Service responses to families may alter dramatically throughout the service system. During discussion, families compared their supports and found that:**

- *a drug and alcohol case manager might transport one parent but not the partner or child*
- *Child Protection may sometimes provide travel vouchers*
- *Disability Services will not provide transport as parents report that Disability Services state they 'are not a taxi service'.*

*Definitions of case management, case coordination, case worker and case support were equally confusing to both workers with university degrees and less well educated participants.*

*Many families highlighted the illogical, uncoordinated and expensive nature of how the various service systems interact. This was particularly evident in case management and in-home or outreach roles where services can only provide limited forms of assistance to one person. Often the parent cannot be assisted with their parenting responsibilities, only one member of a family can be transported, or planning cannot occur around the needs of the whole family in one meeting. The end result being that needs are not met or the family has so many workers involved in their lives that they never have time left to enjoy the benefits of being a family unit.*

*Several families reported feeling isolated, confused, scrutinised and/or controlled by service system involvement.*

*The inability of services such as Disability, Traffic Accident Commission, Child Protection and the Non-government sectors to provide an actual service is felt by many families. Families provided examples where they spent a great deal of time and effort going to meetings to only hear each of these services put forth why their agency or element of the service system cannot provide a service.*

## **Service Gaps**

*Parents report that supports which are adapted to the learning style of individual families are being implemented in some areas but are nearly impossible to access—especially when the children have been removed.*

*One psychologist advised that there are inadequate life-skills programs for parents with disabilities. That it is often not the disability that is the problem but other issues such as the social-cultural background and poverty that are best dealt with through life-skills development.*

## **Implementing Disability Policy and Legislation: Experiences and Issues reported by Victorian families and supporters**

*Disability came and asked me what my goals were and what help I needed. So I told them. They spent the rest of the time telling me why they couldn't help... They must have a lot of practice telling people what they can't do because they sounded like robots' (Parent with a Disability 2009)*

*Some families have reported that Disability Client Services staff are young, inexperienced and, while referred to as specialists in working with people with disabilities, have been ineffectual. One parent advised that the intake worker spoke so quickly, on so many topics, that it was easier to advise that she did not want a service than to try to work out how to understand the worker.*

*Conversely, one family believes that staff from the disability field should be trained in child development to take over from family support services. The outreach worker from Disability Client Services was the only worker they had who communicated effectively, understood the family's needs and could provide practical advice as to how the family could best meet the needs of the child.*

### **Individualised/ flexible Support Packages**

*Parents with a disability report that they are not considered for individualised or flexible support packages now offered to many people with a disability. Families report that they are told not to apply for an Individualised Support Package through the Disability Services Register process as parents with a disability are not considered a priority for service. Other parents have been advised that they can make application if they so choose but delay in receiving support could range from two to ten years. Those who are fortunate enough to have such a package have found that it is not actually adequately flexible and sufficient to support the parenting role and their family unit.*

### **Services When They Are Needed**

*Families can only apply for support from Disability Client Services that is required immediately. Therefore early application for assistance during pregnancy or when the child is out-of-home is not always possible. However immediate response due to service demand and waiting lists is also not always possible when/if the child arrives at home.*

*Some Disability Client Services staff has stated that parenting cannot be classed as a vocation and therefore assistance is not required by legislation.*

### **Equitable Access to Services**

*Parents have also reported that they are advised by Disability Services that they can only receive parenting support if their child also has a disability.*

*Workers advised that equitable opportunities in regard to accommodation are not available from Disability Services and Housing once a woman becomes pregnant. There are no transitional accommodation options for the expectant mother to move from supported to community-based accommodation in a planned and supported manner. Similarly, there are limited options available to women with disabilities who are facing domestic violence.*

## Implementing Child Protection Policy and Legislation: Experiences and Issues reported by Victorian families and supporters

*Most Child Protection workers are pretty good people. I've seen them come and go. We've had five beginning ones in two years. They're young and start off wanting to make a difference. Then they realise that there aren't many support services to help them do their job. At first they really do try to help but no one is helping them. That's when you see them get burnout and that's when it can get nasty.' (Parent with a disability 2009)*

Several parents involved within the child protection system were able to provide examples of how Child Protection and associated services have failed to make reasonable adjustment for their disability. These examples include:

- failure to provide information in accessible formats
- failure to understand disability issues
- the use of discriminatory practices such as only providing courts exaggerated examples of how the impairment might impact on the parents and nothing that acknowledges their strengths.

While policy and legislation aims for an early intervention, crisis prevention approach, the service system is structured to provide a minimal crisis response for many. One family and several service providers felt that most issues result from systemic failure. Other than **Child First**, which is limited in resources, there is no agreed response or targeted resource allocation to assist universal and secondary services to undertake a preventative role. Staff are constantly faced with the inability to make referrals to services that can provide an immediate and on-going response to the family's needs. One legal representative commented that if the estimated \$120,000 spent on one particular court case was spent on practical supports for the family, the case may not have progressed to court.

The Child Youth and Family Act 2005 allows for pre-birth notifications. However with the exception of some programs such as the Royal Women's Hospital Women's Individual Needs clinic there is often inadequate planning and effective pre-natal care and parenting education to prevent removal of the child at birth. Three parents told of being instructed to attend classes or 'to get help' prior to the birth but were not assisted to access the services required. They were not contacted again by services such as Child Protection, Disability Services or any family support services until the child was born.

Current parent assessment options at birth are often limited to facility based options. Parents report these options to be stressful. They do not always have the necessary equipment, physical access and ability to develop systems or specialist knowledge in disability task analysis. One rural family reported that they had to travel 400 km to access a facility-based assessment. Immediate access to services to allow for a transition home from hospital or parenting assessment facility is not always available. Child Protection staff have often relied on these initial assessments to justify their move to placing the child in permanent care rather than working with the service system to make reasonable adjustment for the parents' disability and the child's right to be supported within the family unit.

*The understanding and implementation of stability planning required by the CYAF Act acts against many families and the child's right to be supported within the family unit. Legal representatives have commented that the legislation requires that stability planning (often interpreted to mean permanent care or adoption) should only occur where it is deemed that a return home is not probable. However the process of determining what is probable can be discriminatory. This decision has sometimes been based on the assessments completed when the child was born which fails to recognise the changing situation of both the child and parent and of what could constitute genuine efforts to support the child in-home.*

### **Fear of Child Protection involvement**

*Parents reported that they tend not to ask for help for fear of being singled out, being reported or being scrutinised.*

*One family advised that the fear of Child Protection being involved in their life again was so great that when they discovered they were expecting the next child they planned for an abortion despite being against their personal and cultural values. With advocacy support they have now given birth to a healthy child who is progressing extremely well at home in her parents' care.*

*Three sets of grandparents advised that in hindsight contacting Child Protection was the worst thing they could have done. They felt their children needed help, not legal proceedings, and that the information provided by them in efforts to access services was later presented out of context. They were not advised that the information they provided would be used in court reports. All sets of grandparents remained fearful that more children would be born and removed for lack of knowing how to get support in a timely manner.*

*One mother spoke of a young mothers' group that she had attempted to join but in the first meeting was advised that all of the group facilitator's notes would be available to Child Protection staff. The mother did not return to the group.*

*Parents often point out the disparity in that what may be considered neglect in one family maybe ignored in others. The threshold of what is considered abuse or neglect varies between regions, services, offices and workers. This is problematic when staff are generally young, inexperienced and constantly changing.*

*Many families report that the evidence indicating that neglect is probable in the future is based on sometimes minor incidents that happen in all families and are on occasion exaggerated in Child Protection reports.*

### **The needs of the child and family versus the needs of the system**

*Child Protection staff have openly stated in meetings and court cases that it is easier to find carers for the children if they are under the age of two and have little contact with the biological parent. This creates the risk that assumptions about parental capability are made quickly and bonds with parents are severed to meet the needs of the system rather than the child.*

*Advocates advise that families are often pressured to locate a kinship (family) carer for the children. This can be problematic as parents advise that quite often their own family have provided less than adequate care in the past. However, parents advise that a foster care placement rather than kinship care of their children is harder to organise access. Access regimes become more regimented and time-limited and opportunities to improve parenting skills disappear; all of which makes the children's return home less likely. Parents advised of the inability of the service system to support access opportunities for families and refusal of Child Protection to assist in making up times lost because staff were unavailable.*

*Some parents believe access regimes determined by the courts or Child Protection are generally those requested by Child Protection. They tend to reflect what is easier for Child Protection and the service system and not always what is best for the child and family.*

*One parent reported that she felt that court and child protection staff thought that because she had a disability she was incapable of experiencing emotions such as attachment or grief and loss and therefore contact with the child should be limited.*

*Two parents advised that they could not commit to employment options as the foster care agency refused to assist in providing access on the weekend.*

### **Recommendations - Implementing Policy and Legislation**

#### **Recommendation 5**

Implement effective data collecting processes and research to guide the development of services and funding considerations for parents with a disability and their families.

#### **Recommendation 6**

Undertake immediate review and make appropriate alteration to policy and practices that act as a barrier to parents with disabilities and their families receiving adequate and equitable support from government and community based services.

This Recommendation 6 review should include consideration of:

- The ability of government and the community sector to provide family-focussed strength-based and practical support services relevant to the needs of families who often face multiple social barriers and socio-economic disadvantage/s
- The processes and practices of legal, child and family, disability and community based service systems and the manner in which they interact to impede or promote the well-being of the family unit where the parent has a disability
- The ability of government to create services that may act across all service system boundaries to reduce cross-over and competition between services and government departments acting to protect limited resources

- The requirement of parents with a disability and their families' need for an urgent response and a priority for individualised support packages based on family rather than individual need
- Strategies, funding and workforce development to strengthen community based services' ability to provide effective support to families to reduce the number of professionals involved in family life, to increase the effectiveness of those services and to reduce automatic referral to tertiary level services of Child Protection

## Advocacy

*It was amazing how things turned around. It went from only the advocate being on our side to heaps of services seeing what we could do and working with us. ...services thought we were useless until the advocate got involved. They wouldn't give us any help because they said we couldn't do it. The advocate helped us to show what we could do and now the services can see that with a little bit of help our kids will have the same chances as everyone else (Parent with Disability 2009)*

There is no funded organisation to provide holistic advocacy support to families where a parent has a disability. Access to advocacy generally remains reliant on a family's eligibility for services funded by Disability Services. These services tend to be experts in dealing with Disability Services but not with other service systems such as; health, education, family support and child protection.

Literature in regard to the need for advocacy, both legal and community-based, shows that generalist services are less likely to provide parents with a disability with information about their rights in useable formats and to assist parents to make complaints [12]. To address these issues families need specialised advocates who are aware of all systems including disability and child protection [1].

The majority of families do not have the funds to engage a specialist legal representative at the beginning of a child protection investigation when assessments are being undertaken. Legal representatives are generally not involved in advocating for the provision of services outside of the court room. Legal appeal processes are not available to many and the time delays in these situations furthers the deviancy cycle where expectations are created that an individual cannot parent. Restrictive interventions are then put into place, such as the reduction in access which limit a parent's opportunity to learn [14]. It is hoped that with better advocacy at an earlier stage, contact with specialist services such as Child Protection and costly court cases could be substantially reduced.

### **Advocacy: Experiences and Issues reported by Victorian families and supporters**

#### **Need For Skilled Advocates**

*One family advised that until an advocate assisted them, 'no-one was on their side'. Once the advocate was involved he was able to inform agencies of the family's goals, advocate with services to gain access to support, assist the family in instructing legal representatives, to better understand what was happening in court and to assist the family to undertake a request for a review of case practices.*

*Several families advised that the only advocacy support available to them was from family and friends who did not understand the 'minefield of laws and services'. Several service providers also advised of the difficulty of working with family and friends when acting as advocates who, while well-intentioned, did not understand the complexity and urgency of the situation.*

Several families reported that they did not receive any assistance with locating support until an advocate assisted them to ask 'the right questions'.

Two families advised of Child Protection's refusal to even acknowledge that they were making a complaint until an advocate assisted.

One advocate advised of the lack of guidelines available to assist community-based organisations to help a family make a complaint against Child Protection or to assist the family to contact an advocacy service.

### **Attitudes to advocacy**

*One advocate reported that a Child Protection worker advised a hospital not to have any contact with the advocate even though the parents (the clients) were at the hospital at that point in time.*

### **The Court System**

*Many workers and families talk of the stress and difficulty created by the adversarial nature of the court system. The recent Ombudsman report [3] has created fear that the court system may be removed, reduced or altered within Child Protection systems and processes. However, those same parents who highlighted the difficulties within the court process also highlight their great concern should the court system be altered. It is felt that while it is difficult, the court process at least provides the opportunity for some to be heard and to have child protection processes examined externally. A reduction in the role of legal advocates in the process could lead to a reduction in access to fair and equitable processes for families who feel that they have already been 'forgotten by every part of every system'.*

*Parents with disability note that the Ombudsman did not consult with any parents in his Own Motion Investigation into Child Protection[3].*

*One legal representative advised of the difficulty of meeting the needs of parents with a disability within the Legal Aid system. He advised that there is inadequate time to ensure the client has understood what is happening and what future options may exist. He also advised that it is impossible to spend the time required to go through a judge's decision to explain the decision effectively to their clients.*

### **Recommendations - Advocacy**

#### **Recommendation 7**

Establish and provide recurrent funding of a specialised advocacy service to better support parents with disabilities and their families throughout the state. The aim being that parents are able to access timely and informed advocacy support that adheres to professional standards and ethics.

Recommendation 8

Establish and provide recurrent funding of a specialised service to assist Child Protection, Disability Services and community based services to create information in accessible formats.

Recommendation 9 Establish initiatives to work with the courts, government and community agencies to develop clear guidance and protocols in regard to the sharing of information. The aim being to assist parents with disabilities to access advocacy support to achieve equitable opportunities to participate in complaint and review processes and to receive equitable opportunity to consider and respond to the information being collected, recorded and shared within the service and legal systems.

## **CONCLUSION**

A growing number of Parents with a disability face greater daily challenges and issues in parenting for a variety of reasons. Their lives, their rights and the lives and rights of their children to live with their families seems impeded by a system that can discriminate against them via an assumption that they cannot be a competent and loving parent due to disability. This assumption together with trying to navigate an often hostile, complex and powerful Child Protection & Court system and an inadequate Disability and service support system has meant that many families have been broken apart or are struggling.

Their experience and the experience of disability advocates raises serious questions about the rights and treatment of such people when many layers of disability legislation and policies exist and where a service system seems to have forgotten them.

This report has made a number of recommendations aimed at addressing these very serious matters and we urge those that are able to, to support and fund the recommendations to begin to correct these problems.

## CONTRIBUTORS TO THIS PAPER

### Parents with Disability Community Network

The Parents with Disability Community Project was established in 1996 by parents with a disability and Yooralla's Advocacy and Consumer Participation Worker. It has been supported by Yooralla ever since. It has established the Parents with a Disability Community Network. The aims of the network are to:

- Encourage and empower parents with a disability to be actively involved in directing the project
- Educate the community about the rights of parents with a disability and their needs and issues
- Work with and educate the government and service providers to provide relevant and accessible services to parents with a disability
- Facilitate peer support networks of parents and potential parents who have a disability in Victoria
- Develop an information and resource service for parents with a disability.

### VALID Inc.

The Victorian Advocacy League for Individuals with Disability Inc. (VALID) is an advocacy service for adults with intellectual disabilities and their families. VALID is funded by the Victorian State Government and is managed by an independent committee comprising people with disability, family members and concerned citizens.

### Yooralla

Yooralla is a not-for-profit organisation offering high quality support services for people with disability. Established in 1918, Yooralla offers a wide range of services to people of all ages who are either born with or acquire a disability as the result of accident, ill health or age. 1,500 Yooralla employees work alongside more than 30,000 Victorians with a disability and their families.

Yooralla's vision is a fair go for all people with disabilities. Our mission is to actively support people with disability, their families and carers, in all their diversity, to live the life they choose.

For more information, please visit [www.yooralla.com.au](http://www.yooralla.com.au)

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