



Victorian Equal Opportunity
& Human Rights Commission

Desperate measures

> The relinquishment of children with disability
into state care in Victoria





Victorian Equal Opportunity & Human Rights Commission

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Desperate measures: The relinquishment of children with disability into state care in Victoria

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Victorian Equal Opportunity and Human Rights Commission

May 2012

Foreword

In Victoria today, more than 6,000 children live away from their homes and their families. Whether this is because their parents cannot or should not take care of them is not really the issue; in a wealthy democratic society it is difficult to understand that we cannot provide enough support to parents and families to care for their children.

Human rights law recognises that living as a family is a fundamental right and expectation we all have. In the absence of violence, natural disaster or war, we expect to grow up in our family, to know our parents, siblings and extended family network, to share a common life story and history with them, to be loved by and be able to love them. This is so important to our identity and wellbeing that the right to family is protected in many international laws and in Victoria it is explicitly recognised in the Charter of Human Rights and Responsibilities.

Raising children can be a challenge for any family; raising a child with disability is profoundly more complex. Dealing with multiple systems, service providers, specialists and professionals, government agencies combined with funding barriers and seemingly endless forms is daunting. Furthermore, the systems can be hard to access and navigate and are often crisis-driven, adding layers of complexity and anxiety. This huge strain leads good parents to make the decision to surrender the day-to-day care of their child to someone else.

In *Desperate Measures* we have endeavoured to understand the factors that lead to a family or parent feeling they have no choice but to surrender the day-to-day care of their child to the state. We have heard from parents, organisations that support parents, disability and parent advocates, service providers and practitioners – all have helped us better understand the scale of the issue and the factors that lead to this enormously difficult decision.

What we learnt was that parents in difficult situations need support that is timely, easy to access, flexible and gives them the capacity to continue to care for children with disabilities that can be complex and challenging. We understand that the enormity of that decision and the impact on the future of the family and the child cannot be overstated.

The Commission thanks our Disability Reference Group, in particular Trevor Carroll and Denise Allen, who brought this issue to our attention and helped us initiate the project. Thanks also to the project reference group members who have contributed their expertise, insight and time over the life of the project. Thanks to Commission staff, particularly Michelle Burrell, Senior Adviser Strategic Projects, who invested much time and effort in ensuring this report was developed through an ethical and robust process, and for spending many hours ensuring the families who participated in this project felt that their views and experiences were respected and reflected accurately.

We also acknowledge the many organisations and individuals who contributed their time and expertise through interviews, phone calls, surveys and emails for this research. We acknowledge and thank staff of the Department of Human Services, particularly Argiri Alisandratos and Heather Thomas, who worked cooperatively and transparently with us.

The Commission wants to thank and acknowledge the families and parents we worked with on this project. There were many families we heard about who had considered surrendering their child but there were 16 families and carers who spoke directly to us to share their experience and insight about the issues that led them to this enormous decision – some stopped on the brink – some having fought a long and hard fight with system were too exhausted or unwell to continue. Another 17 families shared their experiences with us by completing our online survey.

We acknowledge their pain and distress at being placed in a position where they had to make this decision. It is not one any of us would want to make about a child we have loved and raised and is an integral part of our life and family.

We welcome the recent initiatives announced by the Victorian Government in response to the *Report of the Protecting Victoria's Vulnerable Children Inquiry* to provide additional support to families, and the government's acknowledgment that vulnerable children are our shared responsibility.

The Commission hopes this report brings attention to the experiences of these children and families in a way that helps us as a community ensure that resources and support are not the reason why children grow up away from the family that loves them.

A handwritten signature in black ink, appearing to read 'Karen Toohey', with a long, sweeping tail stroke extending downwards.

Karen Toohey

Acting Commissioner
Victorian Equal Opportunity
and Human Rights Commission

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Executive Summary

What is relinquishment?

It is well understood that our disability system does not meet demand for services and is crisis driven. This means that families with children with disability do not get the support they need, when they need it, and for as long as they need it. Without adequate support some families reach crisis point.

This crisis can result in relinquishment, where families surrender the day-to-day care of their children to the state. Each year as many as 50 or more families make this heartbreaking decision.

Parents may surrender the care of their child in a variety of settings but, most commonly, children are not collected from facility-based respite. Parents may choose this method because the respite house is a familiar environment. However, relinquishment can take place in a number of locations, including at school, at Department of Human Services (DHS) offices, in hospitals or by calling the police or other emergency services. These children end up living in respite facilities, in transitional houses and in out-of-home care settings such as residential or foster care.

While this complex, varied and traumatic process is often called relinquishment, the word itself does not tell the full story. The term is deeply offensive to families who have acted in desperation and do not want to 'give up' their children. Young people labelled by this term must also deal with the stigma it carries. Importantly, relinquishment also has a specific cultural context for Aboriginal Australians who have suffered a history of dispossession and forced removal from family.

The research

This research project was undertaken using the Victorian Equal Opportunity and Human Rights Commission's research functions under section 157 of the *Equal Opportunity Act 2010* and sections 41(f) and (g) of the Charter of Human Rights and Responsibilities. It looked at the nature, extent and causes of relinquishment, focusing on children under 18 years. The project was promoted by concerns from the Commission's Disability Reference Group and subsequent discussion in the Commission's submission to the Protecting Victoria's Vulnerable Children Inquiry.

This research attempts to shine a light on what has been a hidden problem in our disability service system for many years. It does this primarily through the perspectives of families affected. Seventeen families and carers took part in confidential case study interviews, of which 16 are published. Another 17 families completed an online survey.

The Commission interviewed 19 key informants, asking what factors drive relinquishment, its impacts and what can be done to end it.¹ We also gathered the views of 41 service providers, advocates and support groups through an online survey. In addition, peak bodies and large agencies made written submissions.

1 These included representatives from the Department of Human Services (DHS); the Children's Court; the Victorian Aboriginal Disability Network; major disability, family service and out-of-home care providers; advocates and legal services; the Disability Services Commissioner and Child Safety Commissioner.

Throughout the research, the Department of Human Services (DHS) worked cooperatively with the Commission, in particular by providing data and policy briefings, which has helped build a comprehensive understanding of relinquishment. The department's leadership and willingness to work in partnership with the Commission in exploring this complex issue has been invaluable in helping us to recognise the particular challenges of dealing with relinquishment.

A reference group supported the research. Members included representatives of the Disability Services Commissioner, Child Safety Commissioner, Association for Children with Disability, Youth Disability Advocacy Service and the Commission's own Disability Reference Group.

Limitations of the research

As qualitative research based on a small number of interviews and survey responses, the project had a number of limitations. In particular, the sample size is small and is not randomised. This means that any attempt to extrapolate results as relevant across the whole community is problematic. Further, the case studies in this report naturally provide the perspectives of the interviewees only, and it is understandable that their relationships with organisations and government departments may be strained after many years of seeking help. The case studies should be read with this in mind.

Main findings

Over-representation of children with disability in out-of-home care

In June 2011, there were 4,064 children living in out-of-home care in Victoria, excluding those on permanent care orders.² Those not in permanent care live in family-based placements, kinship or foster care, residential care, secure units or in contingency arrangements.

Of these 4,064 children, 579 have a disability.³ Statewide, 14 per cent of those in out-of-home care identified as having a disability are Aboriginal.⁴

Around 20 per cent of children in residential care are considered by DHS Children, Youth and Family Services (CYFS) to have a disability.⁵ This is significant, as only 11 per cent of all children in care are in residential care.

The over-representation of children with disability in child protection underscores the need for coordinated and seamless support for children who find themselves in the care of the state. If proper, effective disability support is not provided for children with disability when they are in care this may further compromise the life chances of these children, putting their human rights at risk.

2 A permanent care order is an order in child protection that gives both custody and guardianship to a person other than the child's parent or the Secretary. Permanent care orders are made by the Children's Court. *Children, Youth and Families Act 2005* pt 4.10.

3 This is the number of children identified by DHS Children, Youth and Family Services as having a disability. Not all of these children are defined as having a disability under the *Disability Act 2006*. Information provided to the Commission by DHS, 31 January 2012.

4 Data provided by DHS to the Commission, 31 January 2012.

5 That is 101 out of 442 children in residential care or 22.9 per cent. Data provided by DHS to the Commission 31 January 2012.

Prevalence

Currently, there is no systematic recording of relinquishment in Victoria. This makes it extremely difficult to quantify. As a result, the Commission had to rely on indicative measures from DHS and secondary information from organisations to estimate the prevalence of relinquishment.

These sources suggest that 50 or more children and young people are currently in the care of the state following relinquishment.⁶

Thirty-one organisations reported cases where relinquishment was considered in the last two years.⁷ When asked how many cases they knew of, some could identify at least one or two cases. One organisation reported more than 20 cases. More than half reported that relinquishment was more prevalent than two years ago.

People also told us that relinquishment has been happening for many years.

Risk factors

Our research found that families facing relinquishment may only come into contact with child protection because they are unable to access sufficient supports to care for their child. Key informants told us that families in these circumstances share few similarities with those families in contact with the child protection system.⁸ Other child protection concerns are not usually present in these cases.

It is important not to pathologise families or children with disability who are affected by relinquishment. Labelling people in this way masks the strongest predictive factor of relinquishment – unmet need for support. However, thinking about risks can help us to understand some of the factors associated with relinquishment.

In our case studies:

- relinquishment occurred most frequently at around 16–18 years⁹
- in the majority of cases the child had high behaviour support needs
- in the majority of cases the child had multiple disabilities
- in other cases the child had significant physical disabilities or a severe medical condition.

There is no typical family that surrenders care. It is primarily unmet need for services that drives relinquishment; not the disability or nature of the family.

Not every family will reach the ‘tipping point’ – a phrase that came up several times during our research. What seems to make the difference is how the system responds when the family seeks help. Our research found that relinquishment occurs primarily because of the sustained, grinding pressure families are under when they do not get the support they need.

It is important not to pathologise families or children with disability who are affected by relinquishment. Labelling people in this way masks the strongest predictive factor of relinquishment – unmet need for support.

Many people described the disability system as ‘crisis driven’, in the sense that limited resources mean people only get real assistance in times of crisis – while unmet preventative need mounts across the system. This extends to other systems such as education and health, whose actions or inactions can be one of the stress factors that lead to relinquishment.

Our research shows that feelings of being ignored and unheard are both a predictor of relinquishment and a consequence. Families turn to relinquishment as a last resort. In turn, this contributes to deteriorating relationships with government departments, and there is a sense on both sides that options have been exhausted.

6 In this report, state care includes out-of-home care and placements in disability services such as respite centres and transitional houses run by DHS or community service organisations.

7 1 July 2009 to 30 June 2011.

8 The Commission recognises that a lack of effective support also drives contact with the child protection system generally.

9 Of the 17 families who participated in our survey, five had a child with disability aged 17–18 years. Four had a child with disability between 11 and 16 years. A similar age pattern was found in case study families.

Table 1: Potential risk factors for relinquishment

Support context	Family context/impacts	Individual context
Fragmented, inconsistent and hard to navigate service system	Stress and isolation	High behavioural support needs
Lack of a planned or coordinated approach	Carer exhaustion, including where this leads to ill health, depression or anxiety	High support needs as a result of severe physical disability or medical condition
Unmet need for support, including inadequate access to respite, behavioural support and other services	Sleep disturbance, including where parent(s) feel hypervigilant	Adolescence or approaching adolescence
Escalating requests for, and use of, respite and other supports	Safety concerns	
Withdrawal or scaling back of services	Concern for the impacts on siblings	
Suspension or expulsion from school, lack of support from school	Financial pressure	
Transition to adult disability system	Family breakdown	
History of carers reporting that they are no longer able to cope	Single-parent carers being overwhelmed by support needs	
Conflict with government agencies about how best to manage the situation	Feeling unheard – leading to fractured relationships with government departments and service providers	
Workforce capacity issues including skills gaps	Lack of knowledge of rights	

Risk assessment

Currently there is no comprehensive system in place across DHS to identify families at risk of relinquishment. Some regions have developed their own approaches to risk identification and will provide more support to prevent a crisis occurring. The Commission welcomes this; however, a consistent statewide tool is needed in the interests of equity and improved service planning.

A more consistent approach to this type of risk assessment would also help to drive early intervention and prevention, and align with stated policy directions in seamless service delivery.

Current response

Troublingly, for front-line staff in disability settings, there appear to be very few formalised protocols or work directions to guide their immediate decision making or actions when a relinquishment takes place. One key informant called it “working in the dark”.

Parents we spoke to were also unaware of their rights, or who was in charge or the legal arrangements that surrounded their child’s care. However, DHS said there is a clear structure in dealing with needs, and coordination is definitely improving.

DHS informed the Commission that if a child with disability is left in facility-based respite, Disability Intake will be notified and Disability Services at the regional level will organise the immediate response. This includes consulting with the Child Protection Service.

In determining who will lead the DHS response, the questions for child protection involvement are whether the child is at risk of harm and whether the child's parents are wanting to maintain guardianship as demonstrated by their willingness to sign a Child Care Agreement.¹⁰ If DHS considers that there are genuine protective concerns and/or the parents are refusing to sign a Child Care Agreement with an out-of-home care service provider, the usual child protection processes will commence. This may include making a protection application to the Children's Court.

Children may then be placed in out-of-home care. Unfortunately, because relinquishment is not uniformly recorded, there is no accessible data on the number of children who entered out-of-home care as a result of relinquishment. Nor is there data on the types of placements they are living in.

If no protective concerns are present, Disability Services staff will lead the response. We found that there is no dedicated budget in Disability Services to manage these circumstances or discrete capacity in the system to provide emergency accommodation.

Length of stay in respite

If a respite facility is the location for the relinquishment, and Disability Services leads the response, we found that in most cases the child remains there initially – and potentially for a long time. In our case studies, three out of 12 children were placed in a respite facility initially and were still there six months later. In at least one case reported to us a child has been living in respite for two years or more.¹¹

DHS data confirms the trend of long-term stay in respite facilities. In 2009–10, 26 children were in respite facilities for longer than four weeks. In 2010–11 this had risen to 46 children.¹²

Frequency of moves

Children might move between respite centres or, in some cases, to adult respite settings or 'transitional houses'. Multiple moves were a significant trend among the families we interviewed, with eight out of 12 children moved through multiple respite or transitional house settings.

DHS data indicates that in 2010–11, eight children who had been living in respite for more than four weeks were also subject to at least three moves between respite facilities.

Use of 'transitional houses'

To avoid children remaining in respite indefinitely, there is an emergent pattern of DHS opening up houses for older children (16 to 18 years) and funding community-based staff in the properties to support the residents. Generally, these houses have three or four residents.

This model is very similar to the supported accommodation or Community Residential Unit model in adult disability services. These properties are likely to be called 'transitional' or 'emergency' houses.

Among our case studies, four children were placed in transitional houses.

There is currently no system for proactive, independent monitoring and inspection of these facilities to make sure children's human rights are protected.

Family Options

DHS tries as much as possible to avoid placing children in respite centres for any length of time because they are not set up for ongoing care. In some cases the department may approve a Family Options package and a community service provider will attempt to recruit a carer.¹³

In 2011, 20 of these Family Options arrangements were formalised by way of a Child Care Agreement.¹⁴ However, the reality is that some children will not receive this type of placement, regardless of efforts made to secure one.

In some regions, children may stay in the interim home-based placements for six to 12 months awaiting a placement in Family Options, while others wait in respite.

Return home

Some families we interviewed were able to rebuild once proper supports were in place, and so their child returned home. However, this was found to be the exception.

¹⁰ Some advocates felt that in practice this was not so clear cut. See, for example, Key informant 8, Association for Children with Disability.

¹¹ Case study 14: A respite worker's story.

¹² Information provided by DHS to the Commission 31 January 2012.

¹³ The Family Options Program was developed to support families that want to share care of a child with disability with a volunteer carer on a short- or long-term basis.

¹⁴ Information provided to the Commission by DHS, 7 February 2012.

Formalising the placement

Upon relinquishment, for cases that have not gone through the child protection route, parent(s) are required to sign a Child Care Agreement with the service provider that is caring for the child.¹⁵ If parents do not sign an agreement, the Child Protection Service must make a protection application to the Children's Court.

Child Care Agreements are used as much as possible, as this ensures that parents maintain guardianship – which is what most families want. DHS is confident that all children currently in out-of-home care who have entered care through relinquishment are covered by a Child Care Agreement or by an order of the Children's Court, as required by the *Children, Youth and Families Act 2005*.

The Commission welcomes the department's efforts to ensure consistency in approach to Child Care Agreements. However, we remain concerned that parents do not have easy access to legal advice during this process; some families we spoke to were unaware they had signed an agreement.

Human rights implications of relinquishment

Relinquishment caused by the failure to deliver adequate support denies the human rights of children and families at both domestic and international law. In particular, it denies people's rights to the protection of the family and protection of children.

Victoria's Charter of Human Rights and Responsibilities obliges all government departments, and community services organisations delivering services on behalf of the state, to observe human rights.¹⁶ In addition, under the Equal Opportunity Act, these agencies must deliver services to children with disability and their families without discrimination. The Act also requires them to take positive action to eliminate discrimination as much as possible.¹⁷

These Victorian laws provide a clear and unequivocal case that every effort must be made to support families, and to deliver services to children with disability on equal terms with others.

If relinquishment does occur, human rights best interests principles, again protected by domestic and international law, dictate that placements should not cause harm and should meet the rights and developmental needs of the child.

While acknowledging the challenges the system faces, it is difficult to see how a placement in long-term or revolving respite could be in a child's best interests. Further, if conditions in respite or transitional houses are sub-optimal and compromise the child's dignity and wellbeing, this may amount to a breach of rights protected by law.

Impact on children and families

While the number of children entering state care through relinquishment is small compared to the total number of children in care, the impacts of relinquishment are profound – for children, families and the community.

Children experience trauma, grief, fear and confusion. They spend periods in inappropriate and unstable accommodation, which can impact on their future life chances. They experience a loss of connection with their broader community and culture, which can have enormous ramifications for Aboriginal children and their sense of cultural identity. Children from culturally and linguistically diverse communities can also lose contact with their culture.

Relinquishment has severe impacts on families, such as trauma, feelings of anxiety, guilt, shame, and family and health breakdown. Families reported particular concern about the impact on siblings. Along with key informants, families also expressed concern about the deterioration of relationships between families and government departments, and being left out of decision making for their child. Among the families participating in this research, ongoing trauma and grief was the strongest message.

15 In some cases, where child protection is involved, but a protection application to the Children's Court has not been made, a Child Care Agreement might also be used to formalise the placement.

16 *Charter of Human Rights and Responsibilities Act 2006* s 38(1). However, this provision does not apply if, as a result of a [Commonwealth or state statutory provision] or otherwise under law, the public authority could not reasonably have acted differently or made a different decision. *Charter of Human Rights and Responsibilities Act 2006* s 38(2).

17 *Equal Opportunity Act 2010* s 15.

Costs of relinquishment

Relinquishment is costly. It places an additional, unplanned burden on the child protection and disability systems – systems that already struggle to meet demand.

These costs are avoidable. One estimate indicates that placing a child in residential care is seven times more expensive than providing a family with respite two days a week.

In other words, for every dollar spent on respite support, another six dollars can be saved by keeping children out of state care.

Preventing relinquishment

Our research found an overwhelming consensus that the most effective means to stop relinquishment is to address unmet need for support. This will require increased resources across the human services system, including investment in workforce, infrastructure and flexible models of support.

While resource levels are a matter for government, the Commission is concerned that the ability of children and families to enjoy their human rights is compromised when they cannot gain access to the services they need in a timely manner or for the length of time necessary.

This requires a significant increase in budget allocations to disability supports, in addition to funding increases already announced in the 2011–12 state budget. This should be seen as an investment in families and children with disability, particularly as costs of investing in prevention so significantly outweigh the costs of placing a child in state care.

This research also found significant consensus about the practice reforms necessary to prevent relinquishment and the harm it causes. Principal among these is a consistent and flexible response to the whole family's needs, with a much stronger emphasis on early intervention. This is consistent with policy directions across human services and the public health model of protecting children's wellbeing endorsed by the Council of Australian Governments. It is also consistent with the DHS core principle of ensuring that people in need have access to the right support, provided in a cost-effective way.¹⁸

Models of care

A number of preventative models of care were identified in this research. The most frequently mentioned was 'shared care', where the child lives at home several days a week and in a residential or family-based placement for the remainder. Currently, shared care exists in some part under Family Options, and is used in out-of-home care as a means of promoting reunification. However, it is not available on any real scale for the prevention of relinquishment for children with disability.

Although there are challenges in shared care, and noting its particular meaning in Aboriginal communities, the Commission considers that it is worthy of further detailed modelling. Other prevention models should also be investigated, including specialist respite for children with behaviours of concern, intensive behavioural support, the 'affirming families' behaviour program, and a continuum of care for families and children with disability.

Accommodation and support options

The principle that families should raise their children is a sound one, grounded in human rights and established at law. In circumstances where this is not possible, the next best option is likely to be a family-based placement, such as Family Options.

Currently there is a serious gap in support options for adolescents with significant behavioural issues and other complex needs. These young people can end up living in the limbo of relinquishment. As a desperate measure, these children may be placed in transitional houses even with the clear policy direction that this type of accommodation should not be provided to those under 18 years. This is unplanned and unsatisfactory.

A preferable approach is to develop specialist accommodation and support options for older adolescents in a planned way, involving parents and children to design the kind of supported accommodation that will work best for the child. If this were available as an option for families it might prevent the crisis of relinquishment. It might also form part of a planned approach to the transition from children to adult disability services, and provide a more appropriate environment than long-term or revolving respite.

¹⁸ State of Victoria, Department of Human Services, *Human Services: The case for change* (2011) 18.

Central to reconsidering the place of accommodation for older adolescents is making sure that we do not replicate the mistakes of the past, particularly institutional care. Instead, the effort needs to focus on providing support to prevent relinquishment in the first place. However, if we are establishing accommodation options, these should nurture the child's relationship with their family, promote the child's development and meet their emotional needs as they become young adults.

Improving the immediate response

This research identifies a number of improvements that should be made to the immediate response, including the development of consistent, statewide work directions for front-line staff to follow when a relinquishment occurs. Mandatory reporting of relinquishment in the DHS Incident Reporting System and referral of families to independent advice on their rights and responsibilities when entering into a Child Care Agreement would also improve the response.

Family engagement

This research found that a poor relationship between families and service providers, including the DHS and other government departments, often features in relinquishment. Building better relationships is an important part of preventing relinquishment and responding better if relinquishment occurs.

Similarly, respect and mutual learning must underpin relationships with Aboriginal families and communities. Acknowledging the specific cultural impacts of relinquishment on these families and children is the very beginning of this effort.

Noting the positive work of the DHS in a previous project to facilitate family decision making in these circumstances, we encourage the further development of practice methodologies for services and case managers that keep families engaged and support them to rebuild after relinquishment. This will also help to prevent families from feeling that they are being forced to take their child home unsupported, leading to more trauma and grief when they are already struggling with the consequences of relinquishment, and risking another breakdown in care.

Recommendations

Relinquishment is a long-standing, though somewhat hidden, problem. This research attempted to determine the prevalence and nature of relinquishment to create a clearer evidence base from which to respond to the issue. Despite the limitations of this research, clear patterns have been mapped and solutions identified.

The Commission makes the following recommendations:

Action plan for preventing relinquishment

1. That the Children's Services Coordination Board prioritise the development of a coordinated action plan to prevent relinquishment, as part of the proposed Vulnerable Children and Families Strategy recommended by the Protecting Victoria's Vulnerable Children Inquiry.
2. That this action plan to prevent relinquishment be developed in consultation with relevant oversight bodies, including the Child Safety Commissioner, Disability Services Commissioner and the Victorian Equal Opportunity and Human Rights Commission.
3. That when developed, this action plan be monitored and reported on by the Children's Services Coordination Board to these oversight bodies, and to the proposed Children's Services Committee of Cabinet recommended by the Protecting Victoria's Vulnerable Children Inquiry.

Data collection and reporting

4. That relinquishment be a mandatory reporting item on the Department of Human Services' Client Relationship Information System (CRIS) and the Client Relationship Information System for Service Providers (CRISSP).
5. That relinquishment be a mandatory reporting item on the Department of Human Services Incident Reporting System, and that incident reports be subject to independent monitoring and review by the Disability Services Commissioner, similar to current monitoring of out-of-home care by the Office of the Child Safety Commissioner.
6. That the Secretary of the Department of Human Services publicly report on the number of relinquishments – of children under 18 years, young people aged 18 to 25 years and adults – on an annual basis. This should include a regional breakdown of the data and be published on the department website.
7. That the Children's Court of Victoria be resourced to improve its data collection system so that disability and Indigenous status is included in information available to the court to plan its services.

Risk identification

8. That the Department of Human Services develop a flag and review system for identifying and acting on applications to the Disability Services Register that have been waiting for three months or more.
9. That the Department of Human Services develop and implement a comprehensive statewide 'red flag' risk identification system for families at risk of relinquishment.

10. That the Department of Education and Early Childhood Development and the Department of Human Services develop a protocol for sharing information regarding children with disability on reduced attendance arrangements, and those excluded or frequently suspended from school. This should be developed in consultation with the Privacy Commissioner.

Prevention

11. That the Department of Human Services scope, trial and evaluate a range of models of care to prevent relinquishment, in consultation with the disability services and out-of-home care sectors, and invite oversight of this project from the Disability Services Commissioner and Child Safety Commissioner. These models include, but are not limited to, shared care prevention and a continuum of care.
12. That the Department of Human Services scope, trial and evaluate a range of behaviour supports to prevent relinquishment, in consultation with, and with the oversight of, the bodies above. These models include, but are not limited to, specialist respite for children with behaviours of concern, intensive behavioural support and the Affirming Families Program.
13. That the Department of Human Services research, trial and evaluate models of accommodation and support for young people with disability who have high and complex needs, and whose families cannot care full time, in consultation with, and with the oversight of, the bodies above.

Early intervention

14. Using the Family Coaching pilots in out-of-home care as a model, that families identified as at risk of relinquishment be provided with a rapid and early response in order to prevent the family surrendering care.
15. That the Department of Human Services and the Department of Education and Early Childhood Development work together to improve consistency in behavioural supports for children with disability.
16. Building on the Disability Services Commissioner Family Engagement Project and the Department of Human Services Family Decision Making project, that the Department of Human Services develop and provide training on practice methodologies for services and case managers working with families at risk of surrendering, or who have proceeded to surrender, the day-to-day care of their child.

Response

17. That the Department of Human Services develop and implement formal work directions and procedures for staff to follow in the event of a relinquishment, in particular for staff working in facility-based respite, and that these work directions be implemented across Victoria.

Supporting families

18. Mindful of the traumatic impact of relinquishment, that the Department of Human Services develop dedicated trauma support services for families and children who have experienced relinquishment.
19. That the Department of Human Services prioritise the development of dedicated supports for siblings of children with disability as part of its commitment to working with the whole family.

Protecting rights

20. That, consistent with the recommendations of the *Report of the Protecting Victoria's Vulnerable Children Inquiry*, and in order to avoid doubt, the *Disability Act 2006* be amended to include a provision specifying that, when delivering services to children, the best interests of the child are paramount and must be observed at all decision-making points. Further, that this provision specifically refer to the right contained in section 17(2) of the Charter of Human Rights and Responsibilities.
21. That the *Children, Youth and Families Act 2005* be amended to instruct Department of Human Services Child Protection Service staff to refer parents to Victoria Legal Aid for advice when requesting that they enter into a Child Care Agreement, and that Victoria Legal Aid be provided with the capacity to provide such advice to parents or carers considering entering into such an agreement.
22. That the *Administering child care agreements in voluntary out-of-home care* handbook be amended to provide that disability service providers also refer parents to Victoria Legal Aid for advice on signing a Child Care Agreement.
23. That the *Children, Youth and Families Act 2005* be amended to provide a 'non-fault' ground for protection orders in circumstances where families are forced to relinquish care due to lack of disability support services for their children.

24. That a community visitor and advocacy scheme for children in out-of-home care be established in Victoria. This scheme should be adequately resourced to include all children on statutory orders or child care agreements living in non-family-based out-of-home care, including children residing in disability settings.
25. That section 41 (a) of the Charter of Human Rights and Responsibilities be amended to provide that statutory agencies performing an oversight function, and who have identified systemic issues of concern, be able to call for the Department of Human Services or other public authority to request that the Victorian Equal Opportunity and Human Rights Commission review programs and practices to determine their compatibility with human rights.

Shared responsibility and accountability

26. Consistent with the recommendations of the Protecting Victoria's Vulnerable Children Inquiry, that the *Disability Services Child Protection Protocol* be reviewed and strengthened
27. That this review include consideration of the governance arrangements for the implementation of the *Children, Youth and Families and Disability Services Operating Framework* and, in particular, that the role of the Disability Services Commissioner and Child Safety Commissioner be strengthened.
28. That, consistent with the findings of the Protecting Victoria's Vulnerable Children Inquiry and mindful of the link between adverse events within the school system and relinquishment, the Department of Education and Early Childhood Development and the Department of Human Services develop a joint protocol to outline processes for implementing shared responsibility for ensuring that children with disability achieve their full educational potential.

Part 1: Our findings

Chapter 1: About the research

The Victorian Equal Opportunity and Human Rights Commission (the Commission) is an independent statutory body that has functions under the *Equal Opportunity Act 2010*, the *Racial and Religious Tolerance Act 2001* and the Charter of Human Rights and Responsibilities (the Charter).

Our functions include resolving disputes, providing education about human rights and equality of opportunity, undertaking projects and activities aimed at eliminating discrimination and promoting human rights, conducting research, and providing legal and policy advice. In addition, the Commission reports to the Attorney-General on the operation of the Charter and, at the request of public authorities, conducts compliance reviews.

The Commission's interest in relinquishment

Relinquishment is of concern to the Commission because the process engages the Charter rights to equality before the law, protection of the family and protection of a child's best interests. The *Convention on the Rights of the Child* and other human rights protected at international law are also engaged.¹⁹ In addition, Equal Opportunity Act obligations, including the positive duty to eliminate discrimination as far as possible, are relevant.²⁰

In human rights terms, when a lack of access to support services compromises a family's ability to provide effective ongoing care for a child with disability, the right to family and the protection of the child's best interests are put at risk. This jeopardises the life chances of the child, harms families and creates an unnecessary cost burden on the community.

Equality considerations in relinquishment are of particular concern to the Commission because:

- children with disability are over-represented in out-of-home care in Victoria
- there is a well-established link between discrimination and disadvantage
- discrimination may drive disadvantage, which in turn contributes to pressure on families at risk of relinquishment, with serious impacts upon children's immediate wellbeing and their future life chances.

How the project came about

Our Disability Reference Group first raised the issue of relinquishment with the Commission in 2010.²¹ Members were concerned that families may be surrendering their children into the care of the state because they were not given enough support to continue full-time caring.

19 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577 (entered into force 2 September 1990).

20 *Equal Opportunity Act 2010* s 15.

21 This group provides advice to the Commission on systemic discrimination and human rights issues. The group includes members who have direct experience of disability, are parents of children with disability, service providers and advocates.

In the same year, the Disability Services Commissioner and the Child Safety Commissioner were approached by disability service providers with concerns about inadequate service responses to children with disability in out-of-home care.²²

There has also been media interest in relinquishment. One newspaper report stated that there were 40 children with disability in the care of state welfare services, having been surrendered by their parents.²³ Relinquishment was also reported in the consultations for the National Disability Strategy and in the Victorian Law Reform Commission's reference on child protection matters.²⁴

In April 2011, the Commission made representations on the issue of parents relinquishing their children into state care in its submission to the Protecting Victoria's Vulnerable Children Inquiry, chaired by the Honourable Philip Cummins. We recommended:

That issues relating to the nexus between disability services and child protection, and the rights of children and parents with disability are prioritised by the Department of Human Services. In particular, that concerns expressed by parents of children with disability that they are being forced to relinquish their child into care due to a lack of support and respite services be comprehensively examined and resources made available to prevent such relinquishment.²⁵

Project objectives

While many stakeholders acknowledge that relinquishment is a problem, there is no definitive data to establish a direct causal link between the lack of access to disability services and parents surrendering their children. There is no publicly accessible evidence as to the prevalence of relinquishment, what types of arrangements are entered into, and how children and families fare after relinquishment.

This project sought to address that information gap, focusing on the relinquishment of children under 18 years with disability.

The research aimed to:

- give a voice to the families by reporting their stories and experiences of relinquishment to provide a better understanding of the factors leading to that decision
- identify and publish evidence of the nature and extent of families relinquishing their children with disability into care, thereby contributing to the body of qualitative knowledge around disability and child protection
- engage key stakeholders in government, statutory agencies and disability networks to identify systemic factors contributing to the problem
- offer potential policy solutions consistent with Victoria's human rights framework
- facilitate policy and public debate on the issue and solutions.

Throughout this report case studies are used to illuminate experiences and perspectives. All names and identifying details have been changed to protect the privacy of participants.²⁶

22 *Disability Services Commissioner, Annual Report 2010 (2010) 42*; Office of Child Safety Commissioner, *Annual Report 2009–10 (2010) 14*.

23 Carol Nader, 'State has 40 Relinquished Children', *Age (Melbourne)*, 30 September 2010. See also *Elizabeth McGarry, 'Families of the Disabled Still Wait for a Fair Go', National Times, 30 September 2010*.

24 Australian Government, *Shut Out: The Experience of People with Disabilities and Their Families in Australia (2010) 16, 30*; Victorian Law Reform Commission, *Protection Applications in the Children's Court, Report No 19 (2010), 337*.

25 Victorian Equal Opportunity and Human Rights Commission, *Submission to the Protecting Victoria's Vulnerable Children Inquiry (2011) 6*. <http://www.humanrightscommission.vic.gov.au/index.php?option=com_k2&view=itemlist&layout=category&ask=category&id=33&Itemid=496> at 26 March 2012.

26 Case study interviews lasted from one to two hours and notes were taken. All interviewees provided written consent to participate and approved the wording of case studies prior to publication.

Methodology

The project used a qualitative approach that entailed:

- **in-depth case study interviews** with families and carers to document experiences of relinquishment. Interviewees were contacted through family support and disability agencies and others came forward having heard about the research through the media, the Commission website or support networks. Seventeen interviews were conducted, however one family did not proceed with publication of their story. Of the 16 remaining case studies:
 - 12 interviews were with parents who had relinquished a child
 - one was with a parent who had not carried through with relinquishment and was under enormous stress
 - one was with a foster carer of a child who entered care through relinquishment
 - one was with a support person for a mother who had considered relinquishment
 - one was with a worker from a respite facility where a number of children had become resident after relinquishment.
- **an online survey of families** was used by an additional 17 families to tell us about their experiences
- **interviews with key informants** to gain insight into relinquishment. Altogether 19 stakeholders were interviewed using a semi-structured format. These included representatives from the Department of Human Services (DHS); the Children's Court; the Victorian Aboriginal Disability Network; major disability, family service and out-of-home care providers; advocates and legal services; the Disability Services Commissioner and Child Safety Commissioner.²⁷
- **an online survey of organisations** to gather information about demand for disability services and track trends in the occurrence of relinquishment. Forty-one organisations took part in the survey. Of these:
 - 19 were from non-government disability services
 - seven were from government departments or agencies
 - six were from advocacy organisations
 - four were from schools
 - four were from non-government family services.

²⁷ A full list of key informant interviews can be found at Appendix 1.

The remainder were from carers, Early Childhood Intervention Services or other organisations.

- **examination of aggregate de-identified DHS data** to measure the prevalence of families relinquishing their children into care of the state, either through the child protection or disability service systems
- **legislative and policy review** to describe policy and practice efforts to date, and any planned initiatives
- **collation of policy documents and research material** to provide context for the research. This included a comparative analysis with other jurisdictions to identify possible policy solutions that can be localised to the Victorian context
- **identification of policy changes and models of care** to strengthen existing efforts to minimise relinquishment and so improve human rights compliance
- **publication of a final report.**

A reference group supported the project. Its members included representatives of the Disability Services Commissioner, Office of the Child Safety Commissioner, Association for Children with Disability, Youth Disability Advocacy Service and the Commission's Disability Reference Group.²⁸

Limitations of the research

As qualitative research based on interviews with a small number of families and stakeholders this project has a number of limitations, which are outlined below.

The sample

While other data was used to support findings, relying primarily on self-reported experiences necessarily contains some limitations when extrapolating results to the wider community. Nevertheless, the consistency of messages from the families and organisations participating in this research provides powerful evidence of the need to acknowledge that relinquishment is a distressing and traumatic experience, and action needs to be taken to prevent it.

The case studies in this report provide the perspectives of the interviewees only. Often, their relationships with organisations and government departments have suffered from many years of seeking help that, in the view of the family, has not been provided. The case studies should be read with this in mind.

²⁸ One of the Disability Reference Group members is also a member of Respite Action Whittlesea and participated in the reference group in a dual capacity.

Identifying research participants

Survey and case study participants became aware of the research through networks and promotion. This may have led to both over-reporting and under-reporting of relinquishment compared to a random sample; however, given the nature of the topic being researched, it was considered the most appropriate means of recruiting participants.

Aboriginal people

The sample did not include any families who identified as Aboriginal. This means that we were unable to gather views directly from Aboriginal families. However, the Commission values the input of the Victorian Aboriginal Disability Network members, who generously gave their time in a roundtable to discuss the issues. A number of members have direct recent experience of children being relinquished within close family or community, and the insights gained from this discussion were invaluable to the research.

Talking to children and young people with disability

The Commission had hoped to gather the views and experiences of children who had entered care through relinquishment. A survey for previously relinquished children who were now adults was available on the Commission website and was promoted through the Youth Disability Advocacy Service and CREATE Foundation. However, no young people chose to participate. This meant that interviews and surveys were held exclusively with parents and carers.

Relinquishment of people over 18 years

During the research, many people stressed that relinquishment is not limited to children with disability under 18 years. Adults are also placed in care for many of the same reasons, particularly as their parents become older. The Commission acknowledges this and considers it an area worthy of research in its own right.

Parents with disability

Key informants frequently raised the issue of the over-representation of parents with disability in contact with the child protection system. The Commission is concerned that people with disability, in common with all Victorians, enjoy the right to protection of the family provided for by the Charter and at international law.²⁹

²⁹ *Charter of Human Rights and Responsibilities Act 2006 s 17(1); International Covenant on Civil and Political Rights*, opened for signature on 19 December 1966, 999 UNTS 171, art 23 (entered into force 23 March 1976).

Although outside the scope of this research, the Commission considers this issue to be worthy of further detailed research and would welcome the opportunity to work with DHS and the Children's Court on this issue.³⁰

Structure of this report

This report is divided into three sections.

Part 1 summarises the findings from the project, including results of the online surveys, and key informant and case study interviews.

Following an introduction in Chapter 1, drawing upon DHS data and secondary sources, we discuss the prevalence of relinquishment in Victoria in Chapter 2.

In Chapter 3, we identify predictive indicators for relinquishment as we consider the question: What causes relinquishment? The systemic drivers of relinquishment are explored in Chapter 4.

Current responses to relinquishment are analysed in Chapter 5. We then consider the consequences and costs of relinquishment for children, families, community and government, and the human rights implications in Chapter 6.

Chapter 7 focuses on preventing relinquishment. It identifies opportunities for improvement, including where existing policy and practice initiatives might be further developed. Models of care that can better respond to the risk of relinquishment are discussed. The chapter concludes with recommendations.

Part 2 provides the case studies in full.

Part 3 provides contextual information, including a summary of how domestic and international human rights laws intersect with relinquishment. We then briefly describe the Victorian disability and child protection systems. Recent policy initiatives concerning children with disability in out-of-home care are discussed, along with major policy directions in disability and child protection.

A glossary of key terms is provided at the end of this report.

³⁰ The Commission notes the current parliamentary inquiry into Access to and Interactions with the Justice System by People with an Intellectual Disability and their Families and Carers, This is due to report in 2012.

Terminology

Disability

The term 'disability' is used in this report. This reflects the language in the Equal Opportunity Act and the *Convention on the Rights of Persons with Disabilities*.³¹

The Commission notes that international human rights principles and the National Disability Strategy adopt a social definition of disability. Under this model, a person may have a disability but it is society's reaction that has the disabling effect.³²

The Commission recognises that some members of the Aboriginal community do not recognise or use the terminology of 'disability' and prefer the term 'special needs', reflecting the strengths and abilities of people. We acknowledge that Aboriginal people may be unwilling to disclose disability due to stigma or misunderstanding, and that Aboriginal people face significant barriers in accessing support services.

Relinquishment

The term 'relinquishment' is used in this report. The Commission acknowledges that this terminology does not adequately capture the complexity of the issues we are examining and that many families find its use deeply offensive.

There was a very strong negative reaction to the term among the families we interviewed. Many felt that it suggests some form of abandonment. One family spoke eloquently about how, in everybody's interests, there needed to be more than one carer in their child's life, and that this is quite usual for many families.

All the families we interviewed made it very clear that they did not want to give up their children. Not one parent spoke about their child as a 'burden' – they always spoke of the need for support for their family to stay together and of acting out of desperation.

Many families spoke of the inevitability of seeking a place for their child when the system has failed them and, so, their children. As can be seen from the case studies in this report, all are loving parents who felt they were left without a choice.

Key informants were highly attuned to families' concerns around terminology. They shared the Commission's commitment to using language that better reflects the complex circumstances that leads families to the point where they are no longer able to continue to live with their children full time.

Some noted that the language of relinquishment had been around for a long time, with an original connection to adoption in the 1970s. Others noted a more recent increase in the use of the term by the DHS and others.

Some noted that while 'relinquishment' is preferable to 'abandonment', it may still create stigma and shame when families are already traumatised and grieving. Some organisations use the term 'surrender'. While this is by no means a perfect term, it may better reflect how families feel when they reach crisis point.

Others suggested we make it clear that we are discussing the relinquishment of the day-to-day care of the child, not the child.

Others suggested 'yield', 'placement', 'out-of-home care' and 'moving out of home'.

There is no doubt that 'relinquishment' is used as a form of shorthand to describe the wide range of circumstances that the Commission discovered in this research. However, it is a term that lacks subtlety and potentially harms families and children who have already experienced significant trauma.

As a human rights organisation, the Commission wishes to be as sensitive as possible in the way in which it discusses these issues, while also maximising policy impact. In striking that balance we have attempted to use the terms 'surrender' or 'relinquish day-to-day care' as much as possible in the remainder of this report. We have done this to acknowledge that some parents prefer these terms, but we recognise that even this does not adequately capture the nuances of the issue.

Throughout this report, the term 'child' refers to people less than 18 years of age. This is consistent with the terminology contained in the *Convention on the Rights of the Child* and is used for ease of expression.³³ The Commission recognises and respects the distinct needs and experiences of young people.

31 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106 (entered into force 3 May 2008).

32 "Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106, Preamble (entered into force 3 May 2008).

33 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577, art 1 (entered into force 2 September 1990).

Chapter 2: Prevalence of relinquishment

There is very little academic literature on relinquishment. Only one Australian study has specifically investigated relinquishment in the disability sector, and that focused on adults.³⁴

Department of Human Services data

Relinquishment is not routinely recorded by the Department of Human Services (DHS), the Children's Court or any other official body, which makes it extremely difficult to quantify.

There is no standardised entry code for child protection or disability workers to record relinquishment on the department's Client Relationship Information System (CRIS) or Client Relationship Information System for Service Providers (CRISSP). As a consequence, although individual client records on these systems may include notations where a family has threatened to surrender, or has surrendered care, there is no comprehensive dataset.

However, DHS has made its best endeavours to assist the Commission in determining the number of children who entered care in this way in the last year.³⁵

Relinquishment is not routinely recorded, which makes it extremely difficult to quantify.

Child Care Agreement data

Children who enter state care in these circumstances are most likely initially accommodated at a respite centre or other disability setting.

Some may then go into out-of-home care placements arranged by the Child Protection Service. A child may also be placed in a disability setting by a statutory order.

Others may enter a Family Options placement.

If there is no statutory order and a child remains in a disability setting, the parent(s) must sign a Child Care Agreement with that setting. This agreement maintains the guardianship of the parents.³⁶

³⁴ The research found that in the 12 months to March 2009, 32 adults with disability were relinquished into respite care in a state outside Victoria. Karen Nankervis et al. 'Why do families relinquish care? An investigation into factors that lead to relinquishment into out-of-home respite care' (2011) 55(4) *Journal of Policy and Practice in Intellectual Disabilities* 422, 425.

³⁵ In the absence of a reliable measure for relinquishment, we must look to proxy measures and other sources of information. All risk over- and under-counting and should be treated with caution.

³⁶ Child Care Agreements are regulated by the *Children, Youth and Families Act 2005* Part 3.5.

The following was reported by DHS:³⁷

Table 2: Disability Services-based Child Care Agreements

Reporting year	2010	2011
Number of new Child Care Agreements entered into in the previous 12 months ³⁸	21	54 ³⁹
Number of Child Care Agreements that the Secretary is aware exist ⁴⁰	39	39

Of the 39 Agreements the Secretary is aware exist in 2011, 20 are with Family Options services.⁴¹

Limitations of Child Care Agreement data

This data provides an indicative measure for relinquishment, but does not include cases that have gone through the child protection route. That is where Children, Youth and Family Services has facilitated a Child Care Agreement between the family and an out-of-home care provider, or where the Children’s Court has made an order where genuine protective concerns are present.

37 Information provided to the Commission by DHS, 31 January and 7 March 2012.

38 The number of new agreements in the previous 12 months – most of which will have been for less than six months and are therefore not reviewable.

39 It should be noted that more than one agreement can be counted for the same child. A new agreement can also relate to a child that has been in a placement for up to two years, such as when moving from a short-term agreement to a long-term agreement (of which there were 22 in 2011). Information provided to Commission by DHS 7 March 2012.

40 Which includes ongoing agreements that were created earlier than the previous 12 months as well as excluding agreements made during the year that ceased prior to 31 December 2011.

41 Information provided to the Commission by DHS, 7 February 2012.

It should also be noted that from October 2010 to July 2011, DHS undertook a Family Decision Making project that reviewed Child Care Agreements for children and young people in disability care arrangements. This project may have had some impact on the number of Child Care Agreements entered into with disability service providers during 2011.

Family care breakdowns

Family care breakdowns are an indicative measure for relinquishment. DHS defines a family care breakdown as where a parent or carer is no longer able to have their child with disability living at home, and seeks the assistance of DHS. It does not include cases where the Child Protection Service is involved.

DHS regions reported 41 family care breakdowns for children under 18 years in 2010–11, occurring in five out of six regions.⁴² The North and West Metropolitan Region had the highest number of children entering care this way.

This data was collected through consultation with DHS regions. It was not a formal audit of files. As this methodology is not particularly robust, the numbers reported should be treated with caution. However, this estimate is consistent with secondary information gathered from key informant interviews and our service providers’ survey.

42 Key informant interview 16, DHS. Data on family care breakdowns for children with disability over 18 years is not included as it is beyond the scope of this research.

Other measures of relinquishment

Data from families

Of the 17 families who completed our online survey, 13 had considered relinquishment and six had proceeded.⁴³

Of the families in our case studies, 12 of the 13 had proceeded with relinquishment.⁴⁴ One had not relinquished their child at the time of the interview but reported that they were living under enormous pressure.⁴⁵

Data from organisations

Using our online survey, 31 organisations reported cases where relinquishment was considered in the last two years:⁴⁶

- Over half (58 per cent) reported relinquishments had occurred in the same period.⁴⁷
- When asked how many cases of relinquishment they knew of, answers ranged from one or two cases to 15. One organisation reported more than 20 cases.
- Over half reported that relinquishment was more prevalent now than two years ago.⁴⁸

Locations where relinquishment occurred ranged across a wide geographic area; however, there were higher numbers in metropolitan regions, correlating with the distribution of the Victorian population.⁴⁹

In interviews most key informants reported they were aware of between one and five cases of relinquishment, with some suggesting around six to 10 cases were known to them.⁵⁰ One key informant said that they had never seen a case.

The Association for Children with Disability reports that 39 families known to them considered relinquishment in the period from August 2008 to November 2011. A further 14 families proceeded to surrender care in the same period.⁵¹ In the month of November 2011 alone, the Association worked with two families that had surrendered care and two more were actively considering it.⁵²

People told us that this has been happening for many years. A respite worker reported that, over a 10-year period, there has usually been at least one child, sometimes two children, residing full time at his respite facility following relinquishment. He had observed that other respite facilities in the region mirrored that experience.⁵³ The Office of the Public Advocate has noted similar patterns in its annual report of community visitors, identifying young people staying long term in residential respite in some regions.⁵⁴ DHS data indicates that in 2010–11, 46 children stayed in facility-based respite for more than four weeks.⁵⁵

43 Sixteen people answered these questions.

44 Six surrendered care in 2011, two in 2010 and one in 2009. Three took this step prior to 2009. In one case, the child was surrendered at hospital and the family (including the child) then entered the homelessness system.

45 The remaining case studies were provided by carers, support people and a respite worker. One case study was provided by a foster carer of a child who entered care after relinquishment.

46 1 July 2009 to 30 June 2011.

47 Twenty-one of the 36 respondents answered this question.

48 43 per cent reported it about the same prevalence as two years ago. Three per cent said it was less prevalent.

49 Twelve participant organisations were from Eastern Metropolitan region, seven were from Southern Metropolitan Region, eight from North and West Metropolitan, three from Hume and one from Barwon South West. There were no survey participants from Grampians, Loddon Mallee or Gippsland regions. Six were from statewide organisations.

50 For example, the Disability Services Commissioner identified at least seven cases dealt with in 2011 which involved either risks, threatened or actual relinquishments in the context of complaints about the adequacy of adequate supports. Information provided by the Disability Services Commission to the Commission, 5 March 2012.

51 De-identified data provided to the Commission by the Association for Children with Disability, 20 December 2012.

52 Key Informant interview 8, Association for Children with Disability.

53 Case study 14: a respite worker's story.

54 Office of the Public Advocate, *Promoting the human rights, interests and dignity of Victorians with a disability or mental illness, Community Visitors Annual Report 2010–11* (2011), 84, 100.

55 Information provided to the Commission by DHS, 31 January 2012.

Children with disability in child protection out-of-home care

The number of children who have entered out-of-home care through relinquishment is not reported. However, we do know that children with disability are over-represented in the out-of-home care population. Although seven per cent of Victorian children have a disability, among children entering out-of-home care for the first time in 2007–08 the prevalence of disability more than doubled to 15.4 per cent.⁵⁶

More recent data shows that on the night of 10 June 2011 there were 4,064 children living in out-of-home care in Victoria, excluding those in permanent care.⁵⁷ DHS Children, Youth and Family Services (CYFS) identified 579 of those children (14 per cent) as having a disability.⁵⁸

Of the 579 children with disability:

- 82 were identified as Aboriginal (14 per cent)⁵⁹
- 309 were identified by CYFS as having an intellectual disability
- 152 were identified as having a developmental delay or other disability and were under six years of age
- 118 were identified by CYFS as having 'other disability' and were over six years.

Twenty-two per cent of children in residential care were considered by CYFS to have a disability.⁶⁰ This is significant as only 11 per cent of all children in care are in this style of accommodation. By its nature, residential care carries with it additional human rights considerations.⁶¹

56 Victorian Child and Adolescent Monitoring System (VCAMS), 20.3 Children in out-of-home care. <<http://www.education.vic.gov.au/researchinnovation/vcams/parents/20-3inoutofhomecare.htm>> at 27 February 2012.

57 As at 10 June 2011. Data provided to the Commission by DHS, 31 January 2012.

58 Not all of these children may be defined as having a disability under the *Disability Act 2006*. Data provided to the Commission by DHS, 31 January 2012.

59 Data provided to the Commission by DHS, 16 January 2012.

60 That is 101, out of 442 children in residential care or 22.9 per cent. Data provided to the Commission by DHS, 16 January 2012.

61 This is of particular concern when as noted by the Ombudsman, allegations of abuse are significantly higher in this form of placement. While only seven per cent of the out-of-home care population were in residential care in 2006–07, 35 per cent of abuse in care allegations related to this placement type. Such abuse, if substantiated offends the right to liberty and security of the person, as well as the right to protection that all children enjoy. See Victorian Ombudsman, *Own motion investigation into Child Protection – out-of-home care* (2010) 14.

Figure 1: Prevalence of relinquishment: what we know and what we don't know



Chapter 3: What causes relinquishment?

Participants in the research identified a broad range of factors that contribute to relinquishment. These can occur at different times in the life stages of a person with disability, and reflect the complexity of people's experiences of disability and the disability service system.

In the only other previous study of disability-related relinquishment in Australia, researchers identified three domains where predictive factors could potentially be identified.⁶² These are individual characteristics, family characteristics and the support context.⁶³ While this methodology can help us to conceptualise some of the factors associated with relinquishment, it is important not to pathologise families or children with disability. Labelling people in this way masks the strongest predictive factor of relinquishment – unmet need for support.

Individual characteristics

Our case studies described 17 children. Of these children:

- 13 were boys, four were girls
- relinquishment occurred most frequently at around 16–17 years⁶⁴
- in 11 cases the child had high behaviour support needs
- intellectual disability or developmental delay was present in 10 cases
- autism spectrum disorder was present in seven cases
- in three cases, autism spectrum disorder and intellectual disability were both present
- in 10 cases the child had multiple disabilities
- in four cases the child had significant physical disabilities or a severe medical condition.

This pattern of significant support needs, especially in the teenage years, was confirmed by key informants and in our surveys. Although all forms of disability were identified, behavioural factors and the child's physical nature and size predominate when people talk about common factors in relinquishment.

62 However, research from other disciplines including mental health provides some insights into what factors could be predictive of relinquishment. These include service availability, gaps in service provision and service coordination as being some of the key factors that influence parents in the decision making about relinquishment. Power (2008) cited in Nankervis et al., above n 34, 424.

63 Ibid 427.

64 Of the 17 families who participated in our survey, four had a child with disability aged 17–18 years. A further six had a child with disability between 11–16 years.

Many people taking part in our research saw a link between behaviours of concern and relinquishment, particularly in the child's the teenage years. National Disability Services (NDS) Victoria echoed this:

It can be particularly challenging for families supporting children (mainly boys) with severe autism who exhibit behaviours of concern on a regular basis. These behaviours often become more violent from about 12 years onwards as they enter puberty and become physically stronger. The need for behaviour intervention programs can increase at this stage, and these are often not available.⁶⁵

In considering behavioural issues as a potential predictive indicator for relinquishment, the Commission recognises that there is a range of disabilities where behavioural issues may arise, but difficult behaviours do not always accompany these conditions. For example, a child with autism spectrum disorder will not necessarily display behaviours of concern.⁶⁶

We also acknowledge that such behaviours may arise because of the trauma and distress those children with disability experience, rather than because of the disability itself. Most important, however, is to remain focused on the needs of the child rather than defining the young person by behaviours alone:

Above all else, a child who exhibits difficult behaviours is first and foremost a child. This must be our starting point, irrespective of labels of disability that might be deemed appropriate to describe their behaviour.⁶⁷

Interestingly, a few key informants noted a link with severe physical disabilities or high medical needs at a younger age, as well as when the child grew into adolescence. It was reported that where children have very high personal care needs, with teams of carers coming into the home daily, some families could not cope with the loss of privacy and regimentation of family life that this creates. They may also struggle with the physical demands associated with such high care needs.

One key informant reported that it is becoming more common to see younger children entering out-of-home care through relinquishment, with 9–12-year-old children being seen.⁶⁸

Family characteristics

There is no typical family that will consider relinquishment. Distinctive issues arise in each case, based on the individual circumstances and context of the family.

Some have described parenting a child with disability as “navigating uncharted waters”. Families participating in our research spoke of the transformative effect of caring for a child with disability:

Parenting a child with disability is a unique kind of parenting that encompasses many usual childcare practices, plus the need to provide direct assistance in daily living tasks, some medically, educationally and developmentally specialised tasks, as well as the multitude of responsibilities involved in managing a long-term disability.⁶⁹

There is no typical family that will consider relinquishment.

65 National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 2.

66 Difficult behaviour is included in the diagnostic criteria for oppositional defiance disorder and conduct disorder.

67 Association for Children with Disability, *The Behaviour Challenge: Issues and Solutions for Children and Young Adults with Difficult Behaviour* (2005) 3.

68 The youngest child in our case studies was five years old. This child had multiple disabilities with significant medical needs. Another child was surrendered at three months; however, it is understood that this may have been for adoption.

69 Helen Bourke-Taylor, 'Understanding the family's perspective: Parenting a child with cerebral palsy in K Dodd, C Imms & N Taylor (eds) *Physiotherapy and occupational therapy for people with cerebral palsy: A problem-based approach to assessment and management* (2010) 33, 34.

Financial pressures

Families in our case studies were diverse in terms of income, employment and housing status. One was homeless at the time of relinquishment.

Many faced financial pressures. Several parents had to leave employment to look after their child, while some struggled to hold down part-time employment (in some cases multiple part-time jobs). Others faced significant costs for medication, specialised therapies and equipment, additional costs for respite and other services not fully funded, and education costs.⁷⁰

Several key informants noted that relinquishing families tend to be single-parent headed, usually by mothers. In our case study sample, five were female headed, single-parent families (38 per cent). In one of these five cases, a single mother was caring for four children, three of whom had disability. In another, a single mother was caring for two children with disability.

Stress and isolation

Stress and isolation for parents was a very strong theme among key informants and case study families, including where this has led to significant health problems. Impacts on mental health and high rates of depression and anxiety exacerbated by exhaustion were similarly reported in the family survey.

Poorer carer health has been identified previously as a contributing factor to relinquishment.⁷¹

A 2010 study of mothers of school-age children with disability in Victoria reported high levels of anxiety and clinical depression compared with the general population. In that research, 38 per cent of mothers reported depression and 22 per cent reported anxiety disorder.⁷² Examination of groups within this sample revealed that mothers with more than one child with disability, and mothers of children with autism spectrum disorder, all reported “significantly poorer mental health”.⁷³

70 Forty-five per cent of people with disability live in or near poverty. That is more than 2.5 times the rate of poverty experienced by the general population and more than double the Organisation for Economic Co-operation and Development average. PricewaterhouseCoopers, *Disability Expectations: Investing in a better life, a stronger Australia* (2011) 9.

71 Karen Nankervis et al. ‘Respite and Parental Relinquishment of Care: A Comprehensive Review of Available Literature’ (2011) 8(3) *Journal of Policy and Practice in Intellectual Disabilities* 150, 155–156.

72 Helen Bourke-Taylor, Linsey Howie, Mary Law and Julie F Pallant ‘Self-reported mental health of mothers with a school-aged child with a disability in Victoria: A mixed method study’ *Journal of Paediatrics and Child Health* (2011) 4.

73 Ibid. 3.

The same study identified lack of sleep as a key factor in contributing to stress and ill health. Around half of the mothers were unable to sleep through most nights due to the care needs of their child, and half were awoken by their child at least four nights a week.⁷⁴

Case study families frequently mentioned lack of sleep, and the requirement to be vigilant 24 hours a day, as a source of pressure. This was particularly noticeable for parents whose children displayed a tendency to flee or run away, leading them to be hypervigilant out of fear that their child would hurt themselves. It was also acute for parents delivering highly medicalised care to their children.

Siblings

Many participants spoke of concerns for their child’s siblings. These primarily related to sibling needs being met in the face of overwhelming support needs arising from disability. In some cases, this included taking on extra responsibility to help care for their sibling with disability.

Isolation of siblings, typified by finding it difficult to bring friends home, was frequently reported, along with “missing out on the things most children take for granted”:

The whole family felt helpless and exhausted. I worry a lot for my daughter who just tries to go on as if everything is perfectly normal. It is so tough on her and she hides her feelings.⁷⁵

Some identified physical risks for siblings associated with escalating behaviours of concern in children with disability during adolescence. One key informant also identified worry felt by some parents regarding the onset of sexualised behaviour by a child with disability, although this was rarely mentioned by families. More frequent was the trauma and grief of sibling separation upon relinquishment, along with distress when siblings see their brothers and sisters in poor-quality disability settings.

74 Ibid 4.

75 Case study 7: Janeen’s story.

Relationship to the child protection cohort

The risk factors for families in contact with the child protection system are well known. They include substance dependency, family violence, homelessness, parental mental and physical illness and/or disability, poverty, imprisonment, limited social supports and barriers to parent-child attachment. Many of these factors are interrelated. Often they are chronic and multi-generational.

The Department of Human Services (DHS) informed the Commission that Children's Court applications in the relinquishment context are rare.⁷⁶ Our research confirmed that protective concerns other than the parents being unable to continue to be responsible for the day-to-day care of their child are not usually present in these cases.

Only a few key informants could identify instances where other protective concerns arose.⁷⁷ However, as one survey participant noted, "Some high-needs families are forced to pathologise themselves [through the Child Protection Service] to get help." Others noted that some parents might become physically or mentally unwell due to the pressure they are under. In these cases, protective concerns may arise, but it is by no means a pre-determined trajectory.

I knew that to get help I would have to say, "I am going to kill him unless I get some help." So that is what I told them.⁷⁸

'Hitting the wall'

While there is no one story when it comes to relinquishment, the single shared characteristic of families participating in this research was feeling that they were coming up "against a brick wall" when asking for help, and that there were no options left.

As noted by a major out-of-home care provider:

The family is often very articulate. They have gone through high levels of politics and bureaucracy. They end up with many people trying to make something happen, and still nothing happens. Then the family are back to where they started – distraught at not being able to change things.⁷⁹

Some commentators conceptualise this as 'rapid seekership' where parent(s) do as much as they can to get a team of people around the child to support and get the best for them.⁸⁰ If parent(s) cannot get these supports in place, this seekership cannot end, and so the spiral towards family or health breakdown is more likely.

The common characteristic of families was feeling they were coming up "against a brick wall" when asking for help.

⁷⁶ Key informant 16, DHS.

⁷⁷ Key informants from the out-of-home care sector were more likely to note protective concerns. This reflects these organisations' role in providing care to children who have entered the child protection system. One reflected that there could be an overreach by the child protection system because it is built to go down the protective concerns path rather than to provide the intensive support the family needs. That is, there is no clear scope within the disability and child protection systems to cope with the unique circumstances of relinquishment.

⁷⁸ Case study 1: Erica's story.

⁷⁹ Key Informant Interview 19, Berry Street.

⁸⁰ See e.g. Bourke-Taylor, above n 69, 34.

The support context

The health, development and wellbeing of all children is largely dependent on having a healthy and capable caregiver. If parents are not well supported, relinquishment may become the only option.

Organisations consistently reported the following systemic issues and families made similar observations:

The disability system is largely crisis driven, as is the family service and child protection system. Families may be in contact with the service system for many years but support is not delivered at the scale required until the family reaches crisis point.

A lack of long-term planning and early intervention was described as critical. Many observed that disability services struggle to provide the flexible, sustained and family-centred approach that families at risk of relinquishment need.

Significant unmet need occurs across all service types, including facility-based respite, in-home support, day programs, aids and equipment, behavioural support and Home and Community Care (HACC) services. Independent Support Packages (ISP) were reported as unavailable, inadequate or as having their funding reduced.

Unmet need occurs in all regions and is felt acutely in rural and regional Victoria.

Complexity of the application process for the Disability Services Register leads to frustration and contributes to poor relationships between families, DHS and disability service providers. This is exacerbated by long waits for verification and even longer waiting periods for services.

Inaccessibility of the disability services system for Aboriginal families, and poor relationships with family and the Child Protection Service, contributes to families feeling pressured to surrender care. Aboriginal families may be reluctant to make contact because of concerns about discrimination and agency assumptions about parenting skills. Relinquishment in this cultural context is therefore very different for Aboriginal families.

The disability service system deals very poorly with life transitions. This translates to increased pressure on families at transition points, such as adolescence. Family life does not always progress in a neat linear fashion, although service responses appear largely designed in this way.

System fragmentation makes it hard to navigate for families and leads to uncertainty. The stress for families trying to coordinate multiple services (and in some cases dozens of agency carers) contributes to feelings of exhaustion and pressure.⁸¹

Fragmentation also works against coordination and collaboration by organisations seeking to support and sustain families. Where coordination works well, it is more likely as a result of individual relationships rather than system design.

Workforce issues permeate the system.

There are significant challenges in recruiting and retaining quality staff, leading to concerns about the quality of disability services. Relatively low pay and status, casualisation of the workforce and training gaps were reported. This impacts on the way that families experience the disability system – even with the best policy settings in place, without skilled workers families are unlikely to receive effective support.

A lack of staff able to manage behaviours of concern may also lead to the escalation of these behaviours at respite and at home. This may crystallise into families withdrawing their children, becoming even more isolated from support and at risk of relinquishment.

Universal services, in particular schools, may contribute to relinquishment when students with disability are suspended or expelled for behavioural issues, leaving families without any break from caring. Similarly, health services are an important part of the support context for families. If relationships with schools or health providers break down, family feelings of being unable to cope will intensify. For example, in four of our case studies children had been suspended from school prior to relinquishment and, in one case, the school had reduced the child's enrolment to part time.

Secondary services, including family services and Child FIRST, may be inaccessible to families who have children with disability in need of specialised family support.⁸²

These systemic factors are discussed in more detail in the next chapter.

81 Several key informants and survey participants noted that this is exacerbated when the child has behavioural issues and disability service providers refuse to provide service on occupational health and safety grounds, noting that the family may also be at risk in this situation but is left without support.

82 Twenty five out of 37 organisations surveyed reported family support services being 'unavailable or inadequate'.

Predictive indicators

Table 3 sets out some factors that may be predictive of relinquishment. It builds on a model first developed in a previous study of relinquishment into adult disability services, using the findings of our research.⁸³

Table 3: Potential risk factors for relinquishment

Support context	Family context/impacts	Individual context
Fragmented, inconsistent and hard-to-navigate service system	Stress and isolation	High behavioural support needs
Lack of a planned or coordinated approach	Carer exhaustion, including where this leads to ill health, depression or anxiety	High support needs as a result of severe physical disability or medical condition
Unmet need for support, including inadequate access to respite, behavioural support and other services	Sleep disturbance, including where parent(s) feel hypervigilant	Adolescence or approaching adolescence
Escalating requests for, and use of, respite and other supports	Safety concerns	
Withdrawal or scaling back of services	Concern for the impacts on siblings	
Suspension or expulsion from school, lack of support from school	Financial pressure	
Transition to adult disability system	Family breakdown	
History of carers reporting that they are no longer able to cope	Single-parent carers being overwhelmed by support needs	
Conflict with government agencies about how best to manage the situation	Feeling unheard – leading to fractured relationships with government departments and service providers	
Workforce capacity issues including skills gaps	Lack of knowledge of rights	

Immediate events leading to relinquishment

Previous research reports that once a family reaches the point where they decide to surrender day-to-day care of a child with disability, they are unlikely to pull back from that decision.⁸⁴ That research also found that, prior to relinquishment, families told service providers they could no longer cope and would relinquish. Escalating requests for respite and increasing respite use were also noted as predictors for relinquishment.⁸⁵

Our research found the same pattern. In all cases where relinquishment occurred families highlighted a general inability to continue coping as the reason for relinquishment. Most spoke of consistently telling their case manager or DHS that they could not go on. Some specifically used the word 'relinquishment' to describe the crisis they were experiencing when warning DHS that the situation could not continue.

In a few cases, families could identify a specific trigger point, such as hospitalisation of a parent, a violent incident in the home, homelessness or school suspension, but relinquishment was consistently attributed to a lack of any foreseeable options.

⁸³ Nankervis et al., above n 34, 427.

⁸⁴ That study looked at the relinquishment of adult children with disability.

⁸⁵ Nankervis et al., above n 34, 429–30.

Chapter 4: Systemic drivers of relinquishment

It is well accepted that the disability service system in Australia is “underfunded, unfair, fragmented and inefficient and gives people with a disability little choice and no certainty of access to appropriate supports”.⁸⁶

An estimated 80 per cent of total support to people with disability is provided informally by family and friends. Despite this, state governments still face growing demand.⁸⁷

With a 47 per cent growth in the number of people using disability services in the last five years, and a 10 per cent annual funding growth, the system has become crisis driven to the point where it risks the ‘death spiral effect’.⁸⁸ That is, services become more and more targeted so that only those in crisis get a response. Eventually, due to unmet need, the “situation snowballs and more families are forced into crisis”.⁸⁹

Relinquishment is a vivid example of this spiral in individual families and the system itself.

Unmet need

There is significant unmet need for disability services nationally and in Victoria:

- In March 2011, 1,439 Victorians were waiting for an Individual Support Package (ISP), with the value of their requests totalling \$38.6 million. This greatly exceeds the \$23 million available for new packages in that year.⁹⁰

- A further 408 people who already had an ISP had also applied for more funds at that date.⁹¹
- Although waiting times have improved, people are still waiting an average of nearly 18 months for an ISP, although 60 per cent wait less than a year. Almost 200 people had been waiting five or more years.⁹²

Thirteen of the 33 organisations participating in our survey reported more than 70 per cent of their clients were unable to access adequate support services.⁹³ Some organisations reported that none of their clients was able to get an ISP.

Among key informants, one service provider noted that, during the last 18 months, no-one under 18 years had received an ISP package in their region. Others reported similar restrictions on the availability of packages.

In addition, 16 of the 17 families surveyed reported difficulty accessing support services, or that they had received inadequate support services.

- Facility-based respite was most frequently mentioned as being unavailable or inadequate. This confirms findings from previous research into relinquishment in the adult disability system.⁹⁴

86 Productivity Commission, *Disability Care and Support* (2011) 2. <<http://www.pc.gov.au/projects/inquiry/disability-support/report>> at 23 January 2012.

87 PricewaterhouseCoopers, above n 70, 19.

88 Ibid 19–20.

89 Ibid 20.

90 Victorian Auditor-General's Office, *Individualised Funding for Disability Services* (2011) 5.

91 Ibid.

92 Ibid 12.

93 Services reported as unavailable or inadequate included: Early Childhood Intervention Service (ECIS) 70 per cent, and aids and equipment 51 per cent.

94 Nankervis et al., above n 34, 429. An older qualitative survey identified that the disability service system fails to appreciate the importance of addressing the need of the whole family, including children with disability. Importantly, it identified respite as a critical service supporting parents. See La Trobe University, *Listen to Us: Supporting Families with Children with Disabilities: Identifying Service responses that Impact on the Risk of Family Breakdown* (2002), 9.

- In-home care, aids and equipment, family support services and behavioural support were also reported as being unavailable or inadequate.⁹⁵
- Eleven out of 14 families reporting inadequate services had discussed this with case managers. In eight cases, these issues were raised with the Department of Human Services (DHS) Intake Response Team. Overwhelmingly, parents reported receiving no response.
- Not being able to access adequate support often led to stress and deterioration in the parents' mental health.

Unmet need for facility-based respite

Respite services are an essential part of the disability system. Facility-based respite services provide short-term care for children with disability, and allow parents and family to take a break from the caring role. This might be for a few hours, a day or a weekend. As well as benefiting families and carers, respite can provide opportunities and benefits to children with disability.⁹⁶

Properly delivered facility-based respite has the capacity to support families to care for their children well, consistent with a child's best interests and the child's right to protection of the family protected by the Charter of Human Rights and Responsibilities (the Charter) and international law.⁹⁷ It has the potential to provide stability and safety for children with disability and to prevent family breakdown. However, in our study:

- 87 per cent of surveyed organisations reported that facility-based respite was unavailable or inadequate
- National Disability Services (NDS) Victoria reported one member having a waiting list of over 100 families for access to their children's respite⁹⁸
- significant gaps in the availability of facility-based respite for children and young people were also reported.⁹⁹

It is not possible to determine unmet demand for respite services, as vacancy information is not published and DHS does not have waiting lists for facility-based respite services.¹⁰⁰ However, we do know that the total capacity for facility-based respite for children under 18 years is 209 beds in 38 buildings across the state.¹⁰¹

In the last year, DHS has invested significant additional resources in facility-based respite services, with benefits just starting to reach to families. However, from the perspectives of many participating in this research, those resources, while very welcome, are unlikely to meet the current scale of unmet need.¹⁰²

95 Limitations in Home and Community Care (HACC) Programs services were also noted, for example HACC workers are not trained in Percutaneous Endoscopic Gastrostomy (PEG) tube feeding, medication administration or managing challenging behaviour.

96 For example, respite can promote independence and skill development, social interaction, participation in new activities and increased quality of life for the person with disability and their family. Respite Action Whittlesea (RAW) and City of Whittlesea, *Respite needs for the City of Whittlesea* (2011), 1.

97 *Charter of Human Rights and Responsibilities Act 2006* s 17(1), *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577, arts 7, 18 (entered into force 2 September 1990).

98 National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 2.

99 A list of local government areas with no facility-based respite centres for children or adults is included at Appendix 2. It should be noted that people do not need to be resident in a local government area to be eligible to use a respite facility; however, they must live within the DHS region in which the facility is based. The Commission notes that a number of new respite centres are currently being established following funding enhancements in the 2011–12 Victorian state budget.

100 Information provided to the Commission by DHS, 31 January 2012.

101 Information provided to the Commission by DHS, 31 January 2012.

102 The Commission also notes that in 2010 DHS engaged KPMG to develop a statewide strategic plan to provide clear direction for funded respite and carer supports for the next three years. *Developing a Strategic Plan for Disability Services Funded Respite and Carer Support Discussion Paper* (2010).

Recent funding enhancements

The DHS *Funding and Policy Plan 2010–12* includes the delivery of an additional 330 community-managed, facility-based respite episodes in 2010–11.¹⁰³ It includes capital funding for a further 15 facility-based respite places in 2010–11, with recurrent funding to be provided for up to 135 additional respite episodes when these facilities are fully operational.¹⁰⁴

The Commission also welcomes additional resources for Innovative Respite Support. This ongoing funding represents an enhancement to the current supply of children's respite services. It forms part of a \$9.4 million increase in disability services funding announced in the 2011–12 state budget.¹⁰⁵

An additional \$45.1 million in funding is forecast over four years. This includes additional top-up funds to help families meet current cost gaps for aids and equipment, an additional 1,700 days' school holiday respite each year and up to 500,000 hours' additional respite over the four years. Budget forecasts indicate that 23,027 episodes of respite will be provided to adults and children in 2011–12, an increase of 907 respite episodes compared to the previous year.¹⁰⁶

Family experiences of facility-based respite

Some families did not like using facility-based respite because of concerns about the quality of care or the unreliability of the service. Families spoke of the frequency with which respite bookings scheduled months in advance were then cancelled due to their place being taken by another family in an emergency. This leaves families with no real idea of when their next episode of respite might be.

Key informants commented that, upon reaching the top of the waiting list, families might gain only limited hours of service (for example, one weekend's respite every three months). This was confirmed in case studies.

¹⁰³ An episode is "a period of time during which an individual, family or carer receives respite support from an organisation. The period of respite, which can vary from an hour to an entire year, depends on the arrangement for support between the organisation and the individual, family or carer". State of Victoria, Department of Human Services, *DHS Funding and Policy Plan 2010–12* (2011) 135.

¹⁰⁴ Ibid 23.

¹⁰⁵ State of Victoria, Department of Treasury and Finance, *Budget paper No 3 – Service Delivery* (2011) 47–48.

¹⁰⁶ Ibid 47–48, 220.

Waiting so long for so little can lead to further frustration with the service system.

Most respite care options available are for a couple of hours of respite at a time. Many families use this time to run errands, pay bills, visit the school or doctor, or attend to essential family needs:

"A couple of hours here or there doesn't really give them a chance to really rest and recharge."¹⁰⁷

Aboriginal people with kinship obligations must also try to fit these responsibilities into a few hours of facility-based respite.

Waiting so long for so little can lead to further frustration with the service system if the family's needs have increased in that time. Even more frustrating is when children end up being excluded from services due to behavioural concerns that have escalated in the period that families have been waiting. Some families spoke of having to bring their child home after a few hours because the respite facility staff were unable to deal with behaviour incidents.

Other parents stressed the need for a variety of respite services:

There needs to be a recognition that different kids with different disabilities need different types of respite. Often we can't send our daughter to holiday programs (even those designed for special kids) because the activities are just not appropriate for her to participate. We need to ensure kids with high care needs have respite facilities that really cater for them so we parents can get a break from the high level of caring we do every day. Our daughter requires hoists, nappy changes, spoon feeds, bottle feeds. She does not run, bite, hit or tantrum. Her needs are very different to those with behavioural issues and this should be recognised.¹⁰⁸

There has been little research into good practice in the organisation of respite services.¹⁰⁹ Feedback from the reference group for this project highlighted that "getting the right mix of participants" was a key issue for the quality of facility-based respite. Staff skills and experience, particularly in responding to challenging behaviours, is critical. Having this capacity in place is particularly important if facility-based respite services are to avoid excluding children with particular forms of disability or behaviours.

¹⁰⁷ Key informant interview 4, Mackillop Family Services.

¹⁰⁸ Family survey participant.

¹⁰⁹ Nankervis et al., above n 71, 157.

Unmet need for in-home support

In-home support is another form of respite. These services provide in-home carers to assist the family, so that parents and carers are able to take a break. Yet our survey found that 73 per cent of organisations reported that in-home support was unavailable or inadequate.

Some families reported that in-home support did not work for them as they felt they had to be hypervigilant to protect the health and safety of workers, or to be sure that medications or other personal care activities were done correctly. Having multiple teams of carers in the house also caused problems for families. For many, this meant facility-based respite was preferred.¹¹⁰

Families sometimes have to coordinate two, three or more agencies. One client currently has six different providers of different forms of respite. It takes a lot of organisation, energy and stress to coordinate such arrangements. It is also stressful if a carer doesn't turn up for a shift, or is sick and can't be replaced. This happens not infrequently, so families need a lot of resilience.¹¹¹

Among the families we interviewed, what concerned them most was getting a genuine break from day-to-day caring responsibilities. They saw respite as an outcome, rather than a service that must fit within programmatic boundaries.

Among the families we interviewed, there was often a long wait to access both in-home and facility-based respite. Even when families received services, these did not provide the genuine break from caring that they needed to recharge and prevent an escalation of need. This was particularly the case for families who had been engaged in a long struggle to gain services, and for whom what was on offer was simply what was available, not what was needed.

There was often a long wait to access both in-home and facility-based respite. Even when families received services, these did not provide the genuine break from caring that they needed.

Unmet need for behavioural support

Key informants reported long waits and few vacancies in most regions for the Behaviour Support Service (BSS), previously known as Behavioural Intervention Support Teams (BIST).

One in three families surveyed reported behavioural support services were “unavailable or inadequate”. Three out of four organisations reported lack of access to these services.

Key informants told us that families must have a very high level of need to be eligible for the BSS program, so that families are “worn out” by the time BSS arrives. With behaviours and responses further entrenched, families may then struggle to implement the practical, hands-on strategies that are the hallmark of the BSS program. This potentially undermines the program's objectives and risks setting families up to fail.

Key informants noted a lack of coordination between BSS and schools, so that while families are attempting to implement the BSS strategies in the home the school might be taking a different approach to behaviour management. This undermines the prospects of success for BSS interventions and risks further escalation in behaviour.

Fragmentation and complexity

Navigating the disability system is not easy: “Information is scattered across many web pages and documents and people can ‘bounce’ between different DHS staff, disability service providers and advocacy agencies looking for help.”¹¹² Reducing this fragmentation is a key policy priority for DHS.¹¹³

Victoria has led the way in the movement towards individualised funding, based on the principle that people with disability should control their own lives and have access to the support services they need. More than 7,800 Victorians now have an Individualised Support Package (ISP).¹¹⁴ This is a very welcome advance in promoting the dignity and autonomy of people with disability and, therefore, their human rights.

110 See also *National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 2*.

111 Key informant interview 4, Mackillop Family Services.

112 Victorian Auditor-General's Office, above n 90, 8.

113 See e.g. State of Victoria, Department of Human Services, above n 18, 4.

114 Accounting for 19 per cent of DHS disability funds. Victorian Auditor-General's Office, above n 90, vii.

However, for the life-changing potential of ISPs to be realised, the system needs to work fairly and be responsive to need. Currently this is not always the case. ISP complaints now constitute 25 per cent of complaints to the Disability Services Commissioner.¹¹⁵

The Victorian Auditor-General notes: “Accessing an ISP is unnecessarily complex and people are not treated consistently when applying for and planning their ISP. This is leading to inequitable outcomes, which is exacerbated by the fact that demand for ISPs exceeds supply.”¹¹⁶

People who have adequate ISPs are experiencing real benefits. However, among the families who participated in our research, the experience was often time consuming, confusing and did not deliver the services the family needed. This is consistent with the findings of the Auditor-General:

The process is hard for people to understand and requires significant administration. A person's capacity to complete or get help with the application affects its quality and influences the result. DHS staff assess and prioritise applications inconsistently ... These inconsistencies, together with the variable quality of applications, means that acceptance or rejection of the application, and the notional amount of funding and priority status applied, many not actually represent the person's true need and urgency.¹¹⁷

Of specific concern is the Auditor-General's finding that DHS does not have a system to consistently identify and support people at risk of crisis while waiting for an ISP.¹¹⁸ Families considering surrendering care would fall into this category.

People who have adequate ISPs are experiencing real benefits. However, among the families in our research, the experience of getting an ISP was often time consuming, confusing and did not deliver the services the family needed.

It is clear from the families we spoke to that “waiting for ongoing support exacerbates already fragile situations”.¹¹⁹ In some cases, emergency funds are offered. While these may assist in the short term, the ongoing uncertainty and effort needed to renegotiate when emergency payments run out places additional stress on families:¹²⁰

The drip, drip of funding went on for several months. This trickle of funding makes things uncertain and this uncertainty, when you are in desperate need of assistance, is very frustrating and stressful. That is what disables you as a parent.¹²¹

Even when accepted onto the Disability Service Register, the family may then have to wait for approval and funding for a package:

A mother was the primary carer for her husband with cancer, her daughter with autism and her son, who also had some issues. She received two to three hours per week respite in a 12-week block and had to keep re-applying for funding every three months. She was told she would no longer receive funding. She had to beg to receive [Home and Community Care] services. But she was in desperate need of respite. Her Disability Register Application was verified, but she is waiting for support around a year later.¹²²

Having waited for an ISP, families spoke of not being able to purchase the services required because they were no longer available, already fully subscribed or were not the type of support they now required because their needs had escalated.¹²³

Key informants reported packages being approved at funding levels that do not cover the full costs of services. Others suggested that DHS might reduce packages when the amount of funding required is considered unsustainable. One organisation reported a case of support hours being reduced from 72 to seven hours a month, which then triggered a relinquishment.

115 ISP complaints have increased from 15 per cent in 2009–10 to 26 per cent in 2010–11. Disability Services Commission, *Annual Report 2010–11* (2011) 14.

116 Victorian Auditor-General's Office, above n 90, vii.

117 Ibid viii.

118 Ibid 8.

119 Key informant interview 8, Association for Children with Disability.

120 In other cases, a small crisis fund of emergency contingency funding may be available from a community service organisation.

121 Case study 12: William's story.

122 Case provided by regional organisation.

123 This was particularly the case for families who wanted facility-based respite but could only access in-home support, and vice versa. A mismatch between family needs and the availability of behavioural support programs was also frequently mentioned.

Other idiosyncrasies of the system were identified. For example, in at least one region, those in receipt of an ISP are listed as low priority for access to facility-based respite and would be most unlikely to receive a placement.¹²⁴

We were also told that in some areas, Home and Community Care (HACC) services are withdrawn when an ISP is approved, even when an ISP is assessed on the basis that HACC services continue to be provided. This appears to be applied inconsistently, contributing to geographic inequities in how services are planned and delivered.

Other disincentives in the system were reported. For example, when accessing a 'recharge package' of respite of either 35 or 70 days over a year, this must be the predominate form of respite. If this arrangement breaks down for any reason, the family is likely to have lost access to other respite services.¹²⁵

Barriers to support experienced by Aboriginal families

The Victorian Aboriginal Disability Network members identified distinct and profound differences between Aboriginal and non-Aboriginal families' experiences of the disability and child protection system.¹²⁶

Service gaps, complexity and barriers are amplified for Aboriginal families seeking support, due to the long-standing impacts of discrimination, trauma and disadvantage.

They stressed the unique cultural and historical context of relinquishment for Aboriginal communities in Victoria, describing how dispossession and forced removals continue to shape individual, family and community interactions with DHS and other agencies.

124 Information provided to the Commission by Disability Justice Advocacy Inc, 23 February 2012.

125 It was also reported that tensions around unit prices are leading to gaps in service delivery, so that ISPs do not cover the full cost of services, leaving services or families to cover the remaining costs. *National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011)* 3. See also Victorian Auditor-General's Office, above n 90, 31.

126 Indigenous children are 11 times more likely to be in out-of-home care in Victoria than non-Indigenous children. Victorian Child and Adolescent Monitoring System (VCAMS), 20.3 Children in out-of-home care. <<http://www.education.vic.gov.au/researchinnovation/vcams/parents/20-3inoutofhomecare.htm>> at 19 January 2012.

Network members also reported significant barriers to accessing culturally appropriate disability support services.¹²⁷

Although Census data indicates that Aboriginal people have 1.4 times higher disability rates than non-Aboriginal Australians, and four times the rate of intellectual disability, they remain under-represented in the uptake of primary and early intervention services, including disability services.¹²⁸

The service gaps, complexity and barriers to effective support described elsewhere in this report by families and non-Aboriginal organisations are amplified for Aboriginal families seeking support, due to the long-standing impacts of discrimination, trauma and disadvantage that communities face.

Network members spoke of families feeling manipulated into surrendering to child protection because they could not get the services their child needed:

One family told me that they had to relinquish a child because of alleged neglect. They felt unable to cope. They were struggling to balance work, getting enough income, travel to appointments and getting time off work. Their child had complex needs. DHS told them it would be better if DHS looked after the child. They were told, "You can get on with your lives, and you can still have access."

Disability Services planted the seed that the family was not doing a good job. There was no Indigenous organisation involved in the process and no support for the family. The family did not know that there was this mismatch between disability services and child protection – they assumed they would all work together. The parents had work, they were intelligent people – they just needed some support. They could not afford everything. There was no support for the family or for maintaining cultural connection. The child is out of culture now and does not know their family.

127 The Commission welcomes the development of a strategy to promote Aboriginal access and inclusion in disability services. State of Victoria, Department of Human Services, *Enabling choice for Aboriginal people living with disability: Promoting access and inclusion* (2011).

128 Ibid 10.

Feeling unheard

Among families, feelings of being ignored and unheard are both a predictor of relinquishment and a consequence. As families turn to consider relinquishment as a last resort, perceptions of “hitting brick walls” intensify. In turn, this contributes to deteriorating relationships with DHS, typified by mistrust and a sense on both sides that options have been exhausted:

Currently, it has to get to breaking point – they wait for it – they listen over the telephone to see if you are at breaking point before they get you the help you need. It was not until I reached crisis point that DHS really started to listen.¹²⁹

Relinquishment linked to transitioning into the adult system

Participants in this study were asked whether pressures in the adult disability system, particularly unmet need for supported accommodation, may create a perverse incentive for parents to relinquish as a means of guaranteeing their child a place when they reach adulthood.¹³⁰ There were mixed responses. At least one case study participant cited this as a contributing factor:

My friend, whose daughter had a disability, was looking for a placement when her daughter turned 18 – they still didn’t have anything when her daughter died aged 26. I do not want that to happen to my son – that is one of the reasons I had to get him placed now.¹³¹

Several key informants shared that view, although others felt that this was not a predominant factor. These stakeholders considered that families are in crisis when relinquishment occurs, and are not thinking that far ahead. On this analysis, the predominance of 16–17 year olds in the cohort arises because parents cannot see an end to the pressure. Accordingly, if parents knew that a supported accommodation place was guaranteed at 18 years, they may be able to hold on a little longer.

Families are acutely aware of the potentially tragic consequences of an under-resourced adult disability system. Their actions should be seen as reflective of a system that doesn’t provide well for transitions and fails to provide certainty into the future. In these cases, relinquishment is a product

129 Case study 3: Bridget’s story.

130 Unmet need for supported accommodation is well established. See e.g. Parliament of Victoria, Family and Community Development Committee, *Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness Report* (2009) xvi.

131 Case study 1: Erica’s story.

of system distortions in the children’s and adults’ disability systems – both of which are heavily rationed.

Intersections with other systems

The systemic drivers of relinquishment are not limited to the disability service system. As noted by the Protecting Victoria’s Vulnerable Children Inquiry, universal services, such as schools and health providers, are key parts of the support context for vulnerable children.¹³²

Withdrawing these services, or problems in relationships between families and providers, can contribute to pressure on families. When universal services are not available, or do not meet the needs of children with disability, this can contribute to family breakdown and relinquishment.

Protecting the human rights of children with disability is a shared responsibility across government.

Protecting the human rights of children with disability is a shared responsibility across government, yet 30 per cent of surveyed organisations reported school-based supports as being unavailable or inadequate. Half of our case studies identified problems at school.

A suspension or expulsion from, or conflict with, the school was often identified as the underlying cause for the spiral into relinquishment. It may also be the immediate event that triggers surrender of care:

Kenton’s behaviour had really escalated. Apart from some in-home support over Christmas, we had not had respite for nine months. By this stage Kenton had been pulled out of school, so Elizabeth was caring 24/7.¹³³

132 “It is critical that relevant government departments are required to accept their existing responsibilities to vulnerable children and their families and are held accountable for doing so. The Department of Human Services, acting alone, cannot adequately reduce the level of vulnerability for Victoria’s children and young people. The inquiry has found that some government departments, particularly Education and Early Childhood Development and Health, have given insufficient regard to the needs of Victoria’s vulnerable children and young people.” State of Victoria, Department of Premier and Cabinet, *Report of the Protecting Victoria’s Vulnerable Children’s Inquiry* (2012) Vol 1, xxxv.

133 Case study 5: Elizabeth and Ian’s story.

Disturbingly, homelessness was also identified as a trigger for relinquishment:

We were still homeless. I packed up all of Emily's equipment and took her to the hospital and told them I was leaving her there. They tried to refuse me service but I insisted that all our belongings were in the car and I was leaving my child there until we got some help. I had no choice – it was the only way I was going to get a roof over my child's head.¹³⁴

The interrelationship with health services, particularly mental health services, was also noted – both as a means of providing support and as a trigger for relinquishment when adequate care was not provided. Thirty per cent of surveyed organisations reported mental health services were unavailable or inadequate for their clients. Currently, most therapeutic interventions for children are not available until they reach the crisis end of the system.¹³⁵

An over-stretched family support and child protection system was also noted. Some felt that secondary services, including Child FIRST, struggled to be accessible and responsive to the needs of families and children with disability. Regional areas reported significant service gaps; however, unmet need for family support exists across the state.¹³⁶ Others commented that the real challenge was to provide a sufficient amount and range of disability services, so that families did not reach the point of needing Child FIRST services. In other words, disability services should assist the family to avoid a situation where there are significant concerns about the wellbeing of their child.

¹³⁴ Case study 8: Tessa's story.

¹³⁵ See e.g. N Milburn, Royal Children's Hospital Mental Health Service, *Protected and Respected: Addressing the Needs of the Child in Out-of-home Care: The Stargate Early Intervention Program for Children and Young People in Out-of-home Care* (2005).

¹³⁶ See e.g. Ombudsman Victoria, *Own motion investigation into the Department of Human Services Child Protection Program* (2009) 42.

Chapter 5: How does the system currently respond?

Identifying risk of relinquishment

There is no comprehensive, statewide system in place across the Department of Human Services (DHS) to identify families at risk of relinquishment. Nor is there any inter-departmental process for identifying families at risk of reaching the crisis of relinquishment. As a result, relinquishment comes as a shock to the system when it occurs and opportunities to prevent it are lost.

Although there is no 'red flag' system currently in operation, disability case managers do have the ability to monitor how families are coping – indeed, it is part of their role. However, not every family has a case manager. Sometimes the only worker involved is the respite manager and, even if they pick up the signs, they are not in a position to put other (non-respite) supports in place. It is even harder when a family is not connected to disability services at all.

Some DHS regions have developed their own approaches to identifying risk so that staff know what to look for, and will provide more support to prevent a crisis occurring. In at least one region this is now being formalised into more specific risk assessment tools and response.¹³⁷ The Commission welcomes this initiative, and considers that it should be developed statewide.

The Commission was disturbed to hear from families and service providers that, in some cases, DHS staff and case managers are aware of families' intentions, yet take no action to prevent the relinquishment or to better manage what is a traumatic event for all concerned.¹³⁸

We are also concerned that, if a family surrenders care, there is no formal requirement to report this on the DHS Incident Reporting System.¹³⁹ This may occur in some instances but there is no mandatory obligation to report. However, we understand that senior regional staff are notified of relinquishments as arranging a placement has significant funding implications in the immediate term.

Where does relinquishment happen?

Relinquishment occurs in a variety of settings. Most commonly, children are not collected from facility-based respite. Parents may choose this method in the hope it will reduce the trauma for their child, because the respite house is a familiar environment and the child's care details are stored there. However, surrender can take place in a number of locations.

¹³⁷ The Commission understands that some very promising work on identifying triggers for relinquishment and coordinating responses has commenced in North and West Metropolitan Region.

¹³⁸ See e.g. OzChild, Submission to Victorian Equal Opportunity and Human Rights Commission; case study 14: A respite worker's story. Throughout the research, we asked if families were advised to use the word 'relinquishment' in an effort to gain additional priority on waiting lists for services. Opinions were divided on this. Some felt strongly that this was the case. Others did not know of cases where the language had been used in this manner.

¹³⁹ Community service organisations and department staff are mandated to report category one and two incidents. Relinquishment does not appear to be included in either category. See State of Victoria, Department of Human Services, *Critical Client Incident Management Instruction* (2011).

Among our case studies, children were also taken to DHS offices where the parent refused to leave until services were provided. In some cases, police were called after an instance of violence towards the parent or siblings, or relinquishment occurred at hospital or school.

This pattern was confirmed by the remainder of the research. Of the cases known to key informants, the most common site for relinquishment was respite facilities.

Immediate response to relinquishment

Absence of procedures

There appear to be no formalised protocols or comprehensive work directions in place for DHS or community services staff in disability settings to guide their immediate decision making or actions when relinquishment occurs

For example, even though relinquishment is most likely to occur at a respite facility, there does not appear to be a consistent set of directions for respite workers to assist them when relinquishment takes place.

One of the two regions with a centralised DHS respite booking system has developed business rules that mention 'temporary residents'. However, these rules do not set out in detail the roles and responsibilities of respite facility care staff when a child is left at respite.¹⁴⁰ These rules do, however, require the regional Centralised Booking Team to notify the regional Disability Client Services in the event of a relinquishment.¹⁴¹

Nor is there a dedicated budget to manage these circumstances or discrete capacity in the system to provide emergency accommodation.¹⁴²

Who takes the lead?

In the eyes of families and many key informants in this research, responses appear ad hoc and crisis driven. However, from DHS's perspective, the immediate response does have a clear structure and coordination is definitely improving.

DHS informed us that if a child is left in any of the settings above, DHS Disability Intake will be notified. Disability Services at the regional level will organise an immediate response. They will also consult with the Child Protection Service. In determining who will lead the DHS response, the questions for Child Protection Service involvement are whether the child is at risk of harm and whether the parents are wanting to maintain guardianship and will sign a Child Care Agreement. If no protective concerns are present and the parents are willing to sign a Child Care Agreement with an out-of-home care service provider, Disability Services staff will lead the response.¹⁴³

The child protection pathway

If the department determines that the child is at risk of harm, including in those circumstances where the parents of a child requiring an out-of-home placement are unwilling to sign a Child Care Agreement with a service provider, the Child Protection Service will lead the response. In the best interests of the child, Child Protection must make a protection application to the Children's Court to enable the child to be safely placed in the most appropriate out-of-home care available, usually via an interim accommodation order.

Parents may not find out where their child has been placed until they appear in court, usually the next day.¹⁴⁴ However, DHS told the Commission that a decision to deliberately prevent the parents being told their child's whereabouts is the exception and not the rule. DHS informed the Commission that undisclosed placements are only made in circumstances where there is considered to be a clear risk of harm to the child if the parents know of the child's whereabouts.

140 This document covers Case Management, Disability Accommodation Services, Respite Bookings and Respite House Supervisors' roles and responsibilities in relation to a number of scenarios relating to respite and how respite services are delivered in one DHS region. These *Centralised Respite System Business Rules* are not published. Stakeholders report that families feel a lack of transparency about how respite places are allocated and prioritised as they do not have access to such operational policies.

141 If no case management service is involved the regional Centralised Respite Booking Team will refer the individual to Intake and Response for case management. They will also monitor the length of stay (in weeks) and should ensure that a Disability Support Register application has been lodged and given priority status.

142 Key informant interview 16, DHS.

143 Ibid.

144 See e.g. Case study 3: Bridget's story.

Based on the evidence before the court and the best interests of the child, the court will usually make an interim accommodation order returning the child to the care of their parents, to a kinship carer or to the most appropriate other available out-of-home placement (including a respite facility or other disability setting).¹⁴⁵

Interim Accommodation Orders may also specify a range of conditions to address the support needs, primarily of the child, and their family.

Further assessment by child protection practitioners, in consultation with other key stakeholders and service providers, occurs throughout the duration of these orders.

Based on this, the court may then determine that a further interim order is required, or a more long-term order is necessary to ensure the protection and safety of the child.¹⁴⁶

These orders can only be made by the court if it is established that the child is “in need of protection” on specific grounds set out in the *Children, Youth and Families Act 2005*. Unfortunately, as noted by the Victorian Law Reform Commission and others,¹⁴⁷ none of these grounds reflect the unique circumstances of relinquishment, hence orders are made on the grounds of ‘abandonment’ or ‘emotional or psychological harm’.¹⁴⁸

It is important to note that all families we interviewed who had been through the child protection process stressed that they should not have been in the child protection system in the first place. In these cases, families usually said that the Child Protection Service only stepped in because disability services did not. They were also concerned that previous statements they had made about being unable to cope were later used to establish that the child was at risk of harm.

Most found the court process alien, frightening and confusing – some talked about feeling like a criminal. A number of parents also told the

Commission that they had no option but to agree to statements that they had abandoned or caused harm to their child in order to get their child placed appropriately. This concern was shared by a number of key informants:

Paul went to a respite centre for the weekend. I rang them and told them I was relinquishing. They immediately informed the authorities. I think they took Paul to the DHS office the next day. I rang DHS that evening to find out where my son was. They said Paul was at a secret location and I would find out more in court the next day – they were very hostile.

I could not believe it when they brought Paul to court. He looked so shabby – he still had his pyjama top on. I went and bought him food and clothes to get through the day.

They gave me court papers that said I had abandoned my son. The Magistrate didn't want to know the nitty-gritty, they just wanted to know where DHS would place him.¹⁴⁹

Finding an emergency placement

Following relinquishment, the priority is to find a place of safety for the child. Accommodation must be found on the day, which may involve several DHS regional staff working for a considerable time to locate an immediate placement.

Often the child will be placed in a respite centre. Given the capacity constraints in respite services, an ‘emergency bed’ will likely need to be used. This means that another family, also in an emergency, will lose access to respite.¹⁵⁰

Alternatively, the child might be placed in the Interim Placement Program (IPP), which operates in one DHS region.¹⁵¹ Once again, a placement in this program will mean that another family will lose access.

In most cases it appears that the child remains initially at respite. However, one key informant reported that Disability Services in their region is not allowing children to stay at respite in these circumstances. Others reported that DHS will expect the community service case manager to find a solution, either in respite or ‘emergency houses’.

145 In some cases, child protection will agree a course of action with the family prior to court under a Child Care Agreement or following an initial protection application. This could include the child residing in a disability setting such as respite or additional supports being put in place so the child can return to the family home.

146 In some cases, child protection will agree a course of action with the family prior to court under a Child Care Agreement or following an initial protection application. This could include the child residing in a disability setting such as respite or additional supports being put in place so the child can return to the family home.

147 Victorian Law Reform Commission, *Protection Applications in the Children's Court*, Report No 19 (2010) 335–336.

148 *Children, Youth and Families Act 2005* s 162(1) (a) and (e).

149 Case study 3: Bridget's story.

150 Another option is to find an unfunded bed in a community-based respite facility and then fund the child's stay.

151 This is a family-based program delivered by OzChild in the DHS Southern Metropolitan Region. It is designed to give families a short-term break while a family stress factor is dealt with, after which the child returns home. See <<http://www.ozchild.org.au/ozchild/how-we-help/we-support-families/44>> at 3 April 2012.

One key informant expressed concern that the DHS may try to have the child placed with another parent or a former partner of the full-time carer. This occurred even in cases where there had been orders that the parents were to have no contact with each other.¹⁵²

Following an emergency placement, Disability Services or the community service organisation becomes responsible for liaising with schools and organising transport, care plans and other services for the child.

Length of stay in facility-based respite

The clear policy direction is that children with disability should be raised within their families or, if that is not possible, in a family-based placement, such as the Family Options program. However, there are limited Family Options placements available. As a result, children remain in respite or in other emergency placements for much too long.

Our research reveals a disturbing trend of children living for many months in respite facilities.¹⁵³ In some cases, children have been in respite for two years or more.¹⁵⁴ In our case studies, three out of 12 children were placed in respite and were still there six months later.¹⁵⁵

DHS data confirms the trend of long-term stays in respite. In 2009–10, 26 children were in respite for longer than four weeks. In 2010–11 this had risen to 46 children.¹⁵⁶

Table 4: Number of children in facility-based respite for longer than four weeks by region

Region	2009-10	2010-11
North and West Metropolitan	10	11
Southern Metropolitan	5	14
Eastern Metropolitan	8	13
Gippsland	0	0
Grampians	2	8
Barwon South West	0	0
Loddon Mallee	1	0
Hume	0	0
Statewide	26	46

Frequency of moves

In other cases, children move between multiple respite centres including, in some examples, inappropriate respite settings, such as adult facilities. Multiple moves were a significant trend among the families we interviewed. Eight out of 12 children moved through several respite or transitional house settings, or out-of-home residential care.¹⁵⁷ It was also frequently mentioned in surveys and key informant interviews:

Often children will end up in emergency accommodation – often ‘floating’ between four respite houses at a time. We have had times where we have had to book motel rooms with staff because there hasn’t been emergency respite available. This is very unsettling and has huge psychological effects that could be lifelong.¹⁵⁸

DHS data indicates that in 2010–11, eight children who had been living in respite for more than four weeks were also subject to at least three moves between respite facilities. This only occurred in respite facilities managed by community service organisations in two regions.

¹⁵² Key informant interview 8, Association for Children with Disability.

¹⁵³ It should be noted that it may take some time for a family to allow a family-based placement – they may feel their child is more settled at the respite facility. They may also question why a foster family would be better placed to care for their child than themselves.

¹⁵⁴ Case study 14: A respite worker’s story.

¹⁵⁵ The Commission understands that an individualised plan should be developed by the child’s case manager and reviewed every 30 days in consultation with the respite facility.

¹⁵⁶ Information provided to the Commission by DHS, 31 January 2011.

¹⁵⁷ Some families, whose children were placed in out-of-home care settings, struggled with the differing approaches in these facilities compared to disability settings that they were used to, particularly around safety for children who displayed fleeing behaviours.

¹⁵⁸ Organisation survey participant.

In the previous year, DHS reports only one child being moved more than three times, having been in respite for four weeks or more.¹⁵⁹

DHS data does not appear to match the reported experience of families and organisations. This may be because moves between respite facilities are more likely in the first few weeks after relinquishment, while the department seeks options for placement.

Family Options

The principle that families should raise their children is a sound one, grounded in human rights and established at law. In circumstances where this is not possible, the next best option is likely to be a family-based placement, such as Family Options.¹⁶⁰

DHS informed the Commission that regions try as much as possible to avoid placing children in respite centres because they are not set up for ongoing care. In some cases the department may approve a Family Options package and then a community service provider will attempt to recruit a carer.

In 2011, 20 of these Family Options arrangements were formalised by way of a Child Care Agreement.¹⁶¹ However, the reality is that some children will not achieve this type of placement regardless of need or the efforts made to secure one. Providers report they often struggle to find appropriate carers for the Family Options program, particularly for adolescent boys with autism, where there is a growing need.¹⁶²

Yooralla reports that it currently has five children in Family Options after relinquishment. Two are in respite accommodation with approved packages, so Yooralla is actively seeking alternative family-based care.¹⁶³

OzChild reports:

... increasing pressure to place young people in foster care arrangements that are not well suited or matched individually to them and their needs [in order] to take pressure off the accommodation system. Inappropriate placements are often propped up and quality of care issues disregarded by DHS in order to keep kids out of the facility system.¹⁶⁴

In some regions, children may stay in an interim family arrangement for six to 12 months while awaiting a placement in Family Options. OzChild reported children remaining in their Interim Placement Program for 12 to 18 months.¹⁶⁵

Use of transitional houses

To avoid children remaining in respite indefinitely, DHS regions find themselves considering other options.

There is an emergent pattern of DHS opening up houses for older children (16–18 years), and funding community-based staff in properties to support the residents.¹⁶⁶ Generally, these houses have three or four residents.¹⁶⁷ This model is very similar to the supported accommodation or Community Residential Unit model in adult disability services. However, these properties are likely to be called 'transitional' or 'emergency houses'.¹⁶⁸

In one region, there are 10 young people in three transitional houses, although none of these houses are funded recurrently. Other regions have also set up this type of accommodation.¹⁶⁹ Among our case study families, half the children were eventually placed in transitional houses.

Key informants and families raised concerns about inappropriate placements of young people in transitional houses. A number of key informants were concerned about the mix of residents, while some families described poor-quality houses and inexperienced staff.

159 Information provided to the Commission by DHS, 31 January 2012.

160 One parent participating in our online survey who had relinquished care felt that this delivered a good outcome for their child. This parent spoke of an organisation 'finding a wonderful couple' to care for the child.

161 Information provided to the Commission by DHS, 7 February 2012.

162 Key informant interview 17, Yooralla.

163 One young person aged 11 years is now in shared care with a Family Options carer after two years in respite. Key informant interview 17, Yooralla.

164 OzChild, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 6.

165 OzChild reports that continued extensions are sought until DHS provides a Family Options Package. Ibid.

166 Some of the young people will turn 18 there and then transition to adult supported accommodation.

167 Several key informants noted this trend. See also Office of the Public Advocate, above n 54, 105.

168 Out-of-home care residential units are also used; however, this seems to be less common than the use of transitional houses.

169 Key informant interview 16, DHS.

These transitional houses do not appear to be subject to the quality audits or safeguards, such as checks by community visitors, that apply to other disability accommodation services, because they do not fall neatly within the definition of a residential service under the *Disability Act 2006*.¹⁷⁰ Some families expressed significant concerns, with a few making serious allegations of ill-treatment and abuse in previous years.

For other parents, transitional houses worked well for them and their child, provided they could remain actively involved and that staffing and physical arrangements at the property were improved. The keys to success for this option appear to be the mix of residents, the quality of support staff, recognition of the rights, needs and aspirations of the young residents so that the property does not become institution-like and, in particular, retention of full parental decision making:

I roster myself on his team every Saturday and take him out. I want to be as involved as possible. The management of the house doesn't communicate with me, despite the fact that I am at the house every week. I am never told how he spends his time. I have spoken to management about this and was told, "There is an activity list on the wall." Basically, if I don't ask, I am not told.¹⁷¹

Formalising the placement

As discussed above, if there are genuine protective concerns, the Child Protection Service will lead the response and an application to the Children's Court may be made.

Otherwise, upon relinquishment, parent(s) are required to sign a Child Care Agreement with the organisation running the facility where the child

is living.¹⁷² If parents do not sign an agreement, the Child Protection Service will need to become involved and may need to make a protection application to the Children's Court to ensure there are appropriate decision-making mechanisms in place in relation to the child's day-to-day care.¹⁷³ Child Care Agreements do not revoke the custody and guardianship rights of a parent, but enable a placement service provider to make day-to-day decisions regarding the care of the child, preferably in consultation with parents.¹⁷⁴ However, this may not be apparent to families when they are in the middle of the crisis of relinquishment.

Parents may also think that when the Child Protection Service is talking to them about signing a Child Care Agreement with a disability setting they are under investigation.

DHS stressed to the Commission that it has a strong preference to use the least intrusive model. Court action is deemed the last option, and should only be sought in circumstances where no other action can ensure the safety and protection of children, DHS encourages the use of Child Care Agreements – which is what most families want. However, while these agreements do not disturb the guardianship of parents, they do transfer day-to-day care decisions to the out-of-home care or disability provider. They are therefore very significant in the life of the child and family, and may form part of the history of the child if a protection application is later brought before the Children's Court.

The department is confident that all children currently in out-of-home care who have entered care through a relinquishment process are covered by a Child Care Agreement or by an order of the Children's Court, as required by the Children, Youth and Families Act.

¹⁷⁰ The Office of the Public Advocate operates the Community Visitor Scheme. Under the Disability Act community visitors may visit premises that are residential services within the meaning of the Act. They are not authorised to visit people in housing arrangements that fall outside the Act's definition of a residential service. This is of concern, because unless notified of the establishment of the transitional house by DHS, community visitors are unlikely to visit such placements. The Commission acknowledges that the DHS has attempted to clarify the definition of a residential service by developing the Residential Services Information Sheet in August 2011.

¹⁷¹ Case study 1: Erica's story.

¹⁷² Short-term agreements (up to six months) may be facilitated by Child Protection or may be entered into directly with the service provider without Child Protection involvement. If parents sign an agreement with a community service organisation provider, for example a community-based respite facility, this must be reported to the DHS Secretary. Child Care Agreements must be regularly reviewed after six months to make sure the ongoing arrangements ensure in the best interests of the child. The Secretary delegates this task to Child Protection Managers in regions.

¹⁷³ This is because in order to have an effective guardian, a child must be either living with their parents, on a Child Care Agreement, or a court order. However, this may not be apparent to families when they are in the middle of the crisis of relinquishment.

¹⁷⁴ For example, consent to medical treatment if the parent cannot be contacted. See <http://www.dhs.vic.gov.au/__data/assets/word_doc/0014/641111/cyf_infosheet_parents_word_060411.doc> at 15 March 2012.

In the past, there has been confusion at the service level about administration of Child Care Agreements. In 2010–11 the department undertook significant work in this area, which included a review of policies, training for staff, meetings with parents to clarify rights and responsibilities, and an update of the *Administering child care agreements in voluntary out-of-home care* handbook.

However, many of the case study families, whose children stayed in disability services, did not recall signing a Child Care Agreement. In some cases, this may be because the timing of relinquishment was prior to 2010. However, even among families whose children were placed in state care in 2011, parents seemed unaware of their rights and obligations and even the existence of such agreements. The Commission welcomes the effort DHS has made to ensure consistency in approach to Child Care Agreements entered into following relinquishment. However, we remain concerned that parents do not have easy access to legal advice during this process. DHS does not refer parents to advocates when asking parents to sign Child Care Agreements. This is especially concerning since these agreements are made without oversight of the court.

Prospects for reunification

Support for attempts at reunification of a family after relinquishment appears inconsistent. Some families were able to rebuild once proper supports were in place, and their child was able to return home. However, this was the exception among the families we interviewed and those that participated in the survey.

Some families reported intense pressure to take their child home at the point of, and soon after, relinquishment.¹⁷⁵ They did not see this as a genuine attempt at reunification; instead they saw it as a government department trying to avoid its responsibilities when it was unable to find a placement and, in particular, trying to avoid another child ending up in respite full time.¹⁷⁶

We relinquished our son. Within one hour we had phone calls from the service provider and case manager asking what they could do to help. Too late!¹⁷⁷

For those who were able to build a relationship of trust with the department, reunification was possible when an effort was made to engage with the family and the practical supports were provided to ensure the child's return home was viable:

The first two weeks sets the groundwork towards reunification ... we know this from the work with child protection, but it is equally applicable to relinquishment. It is crucial to maintain and build relationships, keeping the family connected and start to build solutions [sic], so that rather than parents feeling they are on their own, parents feel able to take their child home with the support needed for it to work.¹⁷⁸

Shared care through Family Options was identified as positive and planned means to assist reunification. However, relationships in these arrangements need to be handled sensitively and parents given time to recover from the trauma of relinquishment. Departmental representatives and Family Options service providers we interviewed were highly attuned to these sensitivities.

175 Some told us that they had been threatened with losing their parental rights permanently if they proceeded with relinquishment. A small number of key informants also reported this.

176 Some organisations also reported a push back by DHS, either to the family or to Community Service Organisation case managers, to find an accommodation solution.

177 Family survey participant.

178 Key informant interview 14, St Luke's Children, Youth and Family Services.

Chapter 6: Consequences of relinquishment

The impacts of relinquishment are profound. Failure to give adequate support to families, or to respond to relinquishment in a coordinated manner, jeopardises the human rights of children with disability and their families. Each family that we spoke to told us about the deep and persistent trauma and grief of relinquishment. We heard concerns from families and key informants about the quality of care that children and young people receive following relinquishment. Beyond these human impacts of relinquishment, failing to invest in families until they reach crisis point is inefficient, posing avoidable economic costs to the Victorian community.

Relinquishment offends human rights

Relinquishment caused by the failure to deliver adequate support offends the human rights of children and families. In particular, it offends rights to the protection of the family and protection of children.

Under Victoria's Charter of Human Rights and Responsibilities (the Charter) the Department of Human Services (DHS), funded disability services, family services, out-of-home care providers, public schools and health services are legally obliged to observe the human rights of children and families with whom they have contact.¹⁷⁹ In addition, the *Equal Opportunity Act 2010* requires these agencies to deliver services to children with disability and their families without discrimination.

These Victorian laws provide a clear and unequivocal case that every effort must be made to support families, and to deliver services to children with disability on equal terms with others.

It is difficult to see how a placement in long-term or revolving respite could be in a child's best interests.

¹⁷⁹ *Charter of Human Rights and Responsibilities Act 2006 s 38(1)*. However, this provision does not apply if, as a result of a [Commonwealth or state statutory provision] or otherwise under law, the public authority could not reasonably have acted differently or made a different decision. *Charter of Human Rights and Responsibilities Act 2006 s 38(2)*.

As rights holders, every child must be recognised as a unique and valuable human being with distinct needs. Children's rights are not only about legal compliance, they must also be the first consideration in a system that operates to protect children's best interests.¹⁸⁰

Therefore, if relinquishment does occur, the best interests principle dictates that placements should not cause harm and should meet the rights and developmental needs of the child.

It is difficult to see how a placement in long-term or revolving respite could be in a child's best interests. Further, conditions in respite or transitional houses that are sub-optimal and compromise the child's dignity and wellbeing may amount to a breach of rights protected by law.

Equally, if a child's human rights are to be observed, the placement must ensure access to the education, health care, recreation and other services that all other Victorian children enjoy.

Impacts on children

Trauma and grief

They have to leave their parents, brothers, sisters, bedroom, pets, community behind. They experience significant trauma and grief which is often difficult for them to communicate. Often the child lives in a respite house with no consistency until an appropriate carer can be located. They blame themselves for having a disability and feel rejection and worthlessness.¹⁸¹

Unsurprisingly, one of the biggest risks associated with relinquishment, and the greatest concern of parents, is trauma for the child. Families spoke of their children struggling to understand what was happening, and acting out in response to fear and confusion:

He was confused, upset, not knowing his surroundings, he cannot talk, he was frustrated, not sleeping...¹⁸²

Some families were told to limit visits; others struggled to maintain a relationship as both parent and child came to terms with not being able to live together all the time. Others found themselves living a long distance from their child, exacerbating the sense of loss that the whole family feels:

He struggled to understand what was happening, his relationship with me collapsed, he stopped recognising me sometimes when I would visit.¹⁸³

As well as the immediate pain and trauma of separation, we are also aware that young people can be further traumatised by being labelled as a relinquished person. This label can follow them throughout their experiences of state care and beyond.

Quality of life in respite

When looking at a child in respite, knowing they have been there for two years – what effort is being made to give that child quality of life and meet their developmental needs? Respite cannot and should not be regarded as a proper place for that child.¹⁸⁴

This research found that children may spend extended periods in respite facilities, living there as 'temporary residents'. This can be for a few weeks, many months and even years.¹⁸⁵ Children need attachment to develop. Stability – knowing that we will see the same people every day – is a simple part of everyday life for most of us. However, for children in respite there is no such stability:

The child lives in a respite house which over 60 other children access.¹⁸⁶

The changes in staff and residents can be particularly hard for children who need routine and certainty, especially those with autism spectrum disorder. This in turn may lead to escalating behaviours of concern and force relocation to another facility if staff cannot manage the situation:

The children are living in respite – the other people they live with change on a daily basis. They spend weekends at other respite services so their 'home' is able to offer respite to other families.¹⁸⁷

180 "The concept of dignity requires that every child is recognized, respected and protected as a rights holder and as a unique and valuable human being with an individual personality, distinct needs, interests and privacy." Committee on the Rights of the Child, Fifty-sixth session, General Comment no.13: *Concerning the right of the child to freedom from all forms of violence* (2011) CRC/C/GC/13.

181 Organisation survey participant.

182 Family survey participant.

183 Family survey participant.

184 Key informant interview 17, Yooralla.

185 Organisation survey participant. See also Case study 14: A respite worker's story.

186 Organisation survey participant.

187 Organisation survey participant.

Respite facilities are not set up for extended stays. Despite the efforts made by respite staff to ensure children are looked after, attend school and have access to recreation and other activities, the range of services provided can only hope to meet the most basic of a child's needs.

The Commission was also concerned to hear of the inappropriate placement of children in adult respite centres as an emergency measure due to a lack of planned options in the system.¹⁸⁸

The implications of mixing children and adults in the same setting are potentially critical and raise significant concerns for children's safety. It also places an inappropriate burden on staff in adult facilities, who cannot be expected to be experienced or skilled in meeting the distinct needs of children. It was also disturbing to hear of children being placed in motels with support staff.¹⁸⁹

Psychological and health impacts of frequent moves

The kids become 'suitcase kids', moving from one respite facility to another.¹⁹⁰

Some families preferred that their child stayed at one respite setting, especially if their child had previously spent time there and had relationships with the staff. Frequent moves were distressing for the child, sometimes leading to an escalation in behaviours of concern:

He was very upset due to the change in routine. He was familiar with the respite house as he had been going there for some years, but then he was put in a different house. It took about a year for things to settle.¹⁹¹

Quality of life in transitional houses and residential care

It is the only place there is, but it is not the best place.¹⁹²

Some children end up living in supported accommodation, usually referred to as 'transitional houses'. The conditions in these houses appear to vary, with some very disturbing reports by parents of degrading treatment in placements in previous years.

Some families found the houses quite basic and needing to be set up properly for a young person, for example, by buying furniture or making an age-appropriate space in the backyard. However, most important for families was the quality of support staff and the sense that this could become a proper home for their child in a settled environment.

In other cases, children end up living in residential care settings run by out-of-home care providers. Some key informants expressed concerns around the use of residential care for children with disability and, in particular, an inappropriate mix of residents. For example, one organisation told us of a young man with disability living in a house with a young man with a history of sexual abuse and another boy with drug dependency issues – and all three young people are coping with trauma.

Loss of cultural connection

In Aboriginal communities, the whole community cares for the child. When I was with family, this was the only time I could sit down, relax, and talk, because I knew that my child would be cared for, with his cousins. You cannot take a child away from that. Children are enriched by family.¹⁹³

Relinquishment is fundamentally different for Aboriginal people. The implications for the child, family and community when a child enters care are both emotionally and culturally significant. This is not well understood or appreciated in the broader community.

Given the importance of community connection, and of kinship obligations within communities, if an Aboriginal child enters state care through relinquishment, the ramifications are enormous:

Complete relinquishment is horrendous on the whole community. It radiates out in so many ways – the shame of not being able to care for your own child, people forever looking down on you, trying to meet approval and criteria. With continued separation, it gets to the point where you do not know the child and their physical needs, psychological and emotional needs. The damage to the relationship becomes greater than the problem in the first place.¹⁹⁴

Relinquishment is fundamentally different for Aboriginal people.

188 See e.g. Case study 2: Belinda's story.

189 "We have had times where we have had to book motel rooms with staff because there hasn't been emergency respite available. This is very unsettling and has huge psychological effects that could be lifelong." Organisation survey participant.

190 Organisation survey participant.

191 Family survey participant.

192 Case study 13: Karen's story.

193 Key informant interview 18, roundtable with members of Victorian Aboriginal Disability Network.

194 Key informant interview 18, roundtable with members of Victorian Aboriginal Disability Network.

Despite the importance of these cultural factors, current responses to relinquishment do not appear to be cognisant of these implications for the child:

The issue of future shame to the child and family was completely ignored. The parents had given up their child, thinking they were getting the best life on offer for them, but the child ended up in exactly the same boat. There was no benefit to the child whatsoever.¹⁹⁵

Given the impacts upon a child's sense of cultural identity, relinquishment resulting from a lack of effective support to the child and family undermines that child's legal right to enjoy their culture, protected by the Charter and at international law.¹⁹⁶ This is in addition to other potential risks of human rights breaches.

Risks to future life chances

At this time, no work has been done to examine the specific post-care outcomes for children with disability in either disability or child protection settings. However, it must be acknowledged that relinquishment brings with it the risk of poorer life chances.

It is well understood that those leaving out-of-home care continue to experience poorer outcomes across a range of social indices, including health, education, employment and housing.¹⁹⁷

Individuals' life outcomes are influenced by their experiences of care, especially instability in placement. This in turn affects the sense of belonging and certainty in relationships that most Victorians take for granted. Outcomes are also known to be influenced by the nature and quality of support received by an individual during their transition from care.¹⁹⁸

195 Key informant interview 18, roundtable with members of Victorian Aboriginal Disability Network.

196 *Charter of Human Rights and Responsibilities Act 2006*, s 19.

197 See e.g. Joseph McDowell, *CREATE Report Card: Transitioning from Care in Australia* (2009).

198 The Commission welcomes the establishment of the Springboard program to facilitate employment and learning opportunities for those leaving care, and notes that funding of \$16.9 million has been allocated to this initiative over four years. The State Government of Victoria has also announced \$1 million funding for a major longitudinal study of care leavers.

Impacts on families

Trauma and grief

All of the families who participated in this research spoke of trauma and grief – for themselves, their children with disability and their other children. This trauma lasts for many years after the child leaves home. It does not dissipate. Even so, not a single family participating in this research was offered specialised trauma counselling.¹⁹⁹

Left with little choice but relinquishment when confronted by seemingly insurmountable barriers to support, parents still expressed feelings of guilt and shame. In many cases, this was reinforced by the system, particularly if families were catapulted into the child protection system.

For families, taking their child to the DHS office or calling the police was an act of protecting the safety of their child and family – it was not an act of abandonment or harm. Families felt the system had labelled them as bad parents. They felt shame and guilt, even while feeling they had no other choice but to take this step.

Trauma, anxiety and stress is also felt by families thinking about relinquishment, especially if they have no-one to confide in about the conflict they feel in considering this option:

I feel bad even considering the possibility of relinquishment. It feels like I'm a failure and I would have trouble saying it out aloud.²⁰⁰

This shame is intensified because relinquishment is not openly discussed in the community and is very misunderstood. The term relinquishment is itself deeply offensive to many families, as it reinforces the idea that families have given up their child. This research confirms that nothing could be further from the truth. Families continue to love and care for their child; they simply need support options that will work:

Being a carer is lonely and no-one can understand how it feels to reach the end of the road. We believe the department could have responded to our plight much more sensitively and recognised that we were going through trauma, guilt and shame. If we could have worked together to find a solution, that would have been much better than going into damage control.²⁰¹

199 The Commission notes that the Family Relationship Services for Carers is a statewide counselling service, funded by the Commonwealth. See <<http://www.each.com.au/family-relationship-service-for-carers>> at 15 January 2012.

200 Family survey participant.

201 Case study 11: Sandra and Tom's story.

Family breakdown

A number of families we interviewed had experienced relationship breakdown either during or after relinquishment.

Caring for a child and not receiving the needed support creates intense pressure on relationships. If relinquishment occurs, the emotional stress and trauma may be too much for a relationship to withstand. This goes beyond parental relationships to extended family, including grandparents, siblings and other important people in the child's life:

It tore our family apart. I nearly divorced my husband and my extended family felt anger, grief, sadness and helplessness.²⁰²

Four families relinquished to DHS. Three marriages ended.²⁰³

Sibling wellbeing compromised

Concern for siblings was one of the strongest themes in this research. Many families spoke of the ongoing impact sibling separation had on their children, even though siblings have had to miss out on a lot due to the high care needs of their brother or sister. Families and key informants alike highlighted the trauma and grief of sibling separation upon relinquishment. Siblings may also feel resentment and anger towards their parents, who themselves are dealing with the grief of separation.

Added to this is distress for siblings seeing their brothers and sisters in poor-quality disability settings, or far from home. All this contributes to the human cost of relinquishment, acutely felt by the whole family:

Our daughter particularly suffered. She was very close to her brother and was deeply affected by what he was going through. She struggled with depression. One day I arrived home to find she had taken her life.²⁰⁴

Currently, there appears to be very little in the way of support for siblings generally, and nothing at all provided to those directly affected by relinquishment. This is a significant service gap.

Depression and ill health

Breakdowns in physical and mental health were frequently mentioned by families and organisations as a consequence of relinquishment. Several of our case study families had experienced significant health problems as a result of stress associated with considering or proceeding with relinquishment:

It made our lives hell... I couldn't stop crying and I thought about suicide a lot.²⁰⁵

The effect was so overwhelming I tried to commit suicide. I felt so much guilt and I felt I neglected him. I feel I was a bad mother for doing this. I didn't have many choices. I went through this nightmare and hell and now suffer depression.²⁰⁶

Parental rights disregarded

A strong message from families was that they did not surrender their responsibilities as parents. Parents want to continue to be parents but the reality is that they can no longer do so with their child living full time at home.

In most cases parents maintain legal guardianship. However, these rights feel distant for families negotiating the daily care of their child once they are living full time in respite or other placement. They feel isolated from their child, are rarely informed of their rights and feel caught up in a system that does not listen to them or their child.

A common theme was that parents felt 'locked out' from decision making and not valued as the people who knew their child best. These concerns are exacerbated if the parents have had previous experiences of poor relationships with case managers, government departments or service providers.

Among the families we interviewed, lack of control was intensified in settings of poor quality, or those otherwise inappropriate for a child, and when there was uncertainty about how long the placement would last. Parents often attended facilities daily to make sure proper care was given, or put themselves on the roster as carers so that they could stay involved with what was happening.

202 Family survey participant.

203 Organisation survey participant.

204 Case study 6: Robert's story.

205 Family survey participant.

206 Family survey participant.

Poor relationships with government departments

You are always told that there is someone worse off than you are. That is the life of a parent of child with disability.²⁰⁷

To many families, the system simply lacks empathy.

Many parents talked of being poorly treated by case managers, disability service providers and the DHS – suggesting that policy commitments to ensure service users are “valued, respected and treated fairly at all times” do not always translate into practice in a competitive and under-resourced system facing significant workforce issues.²⁰⁸ Poor relationships with the Department of Education and Early Childhood Development and health services were also reported.

For many of our case study families, relationships had become fractured after years of seeking support, with both sides feeling they had run out of options. The crisis in these relationships was particularly felt at the point of relinquishment, with some families reporting that even when they told their case manager that they were about to surrender care, they were not believed:

After two years of trying to get behaviour support and being told ‘no’ – we knew we had reached the end. We left Jack at his school in 2011. We rang them and said we were not taking Jack home. The school rang DHS to tell them we had relinquished. I understand that the DHS response was that we wouldn’t go through with it. But we did. Jack was put in a respite centre for a few days. The school told me where he was – DHS did not give me any information.²⁰⁹

To many families, the system simply lacks empathy. Feelings of being unheard, or of being in a struggle with the system, sometimes infects all future relationships with DHS. Some said that having been let down so many times before, they were unlikely to trust DHS to protect their child’s best interests.²¹⁰

However, some families were able to build positive relationships with DHS and service providers once the child had left home, so long as the parents could maintain decision-making power and be actively involved in the care of their child.

This also appears dependent on having clarity about who was leading the DHS response. In particular, the role of a good quality case manager makes a difference to rebuilding relationships.

Costs to the community

It makes financial sense to invest in supporting families to care for children with disability. Failing to respond until families reach crisis is inefficient, and leads to serious consequences for the child, family and community.

On average, it costs more to care for a child out of the home than it does to provide families with support to continue caring. Our research suggests that it costs 18 times more to place a child in a disability residential service than to provide regular respite two times a month.²¹¹

Keeping a child living in a respite facility is also economically inefficient. In 2010 the annual running costs for one bed in a respite facility was in the order of \$120,000.²¹² In contrast, Respite Action Whittlesea (RAW) and the City of Whittlesea estimate the cost of 24 days of weekend and holiday respite (two nights a month) at \$6,723.

One key informant estimated that it might cost \$30,000 annually to provide intensive, preventative respite for a family in crisis.²¹³ That is around two days per week respite.

In May 2010 the Ombudsman indicated that the average annual cost of an intermediate child protection residential care placement was \$143,489, while a complex residential care placement cost \$205,382.²¹⁴ This suggests that the cost of relinquishment into child protection is in the order of five to seven times the cost of intensive respite support.

207 Case study 10: Kalliana’s story.

208 State of Victoria, Department of Human Services, above n 18, 18.

209 Case study 4: Janis’s story.

210 Interestingly, one parent recalled that working with child protection was more positive than disability services.

211 Based on a cost of \$6,723 per year for two days a month respite, compared to \$127,000 per annum for placement in a disability residential setting.

212 Danielle Green MP, “Whittlesea gets a much needed respite care centre” (Media release, 3 September 2010).

213 Berry Street estimated the cost of caring for a child in child protection residential unit at \$215,000 a year, with the cost increasing to \$300,000 for therapeutic care – ten times as much as intensive respite. Key informant interview 19, Berry Street.

214 Ombudsman Victoria, above n 61, 76.

Long-term residential placements in disability services are similarly costly. In 2009–10 the cost of disability-funded accommodation within government-provided services was \$127,000 per person.²¹⁵

Based on these figures, even intensive respite should cost less than a residential placement in either child protection or disability facilities:

- It costs four times more to place a child in a disability residential service than to provide intensive respite
- It costs up to seven times as much to place a child in out-of-home residential care than to provide extensive respite.

Table 5: Costs of support options

Service	Estimated cost
Personal support (in-home, community access, one-on-one support)	\$37.30 per hour ²¹⁶
Respite (in-home or community worker)	\$37.30 per hour ²¹⁷
Two nights respite per month	\$6,723 per year ²¹⁸
Intensive respite	\$30,000 per year ²¹⁹
Disability shared supported accommodation	\$127,000 per year ²²⁰
Full-time placement in facility-based respite	\$120,000 per year ²²¹
Intermediate child protection residential care placement	\$143,489 per year ²²²
Complex child protection residential care placement	\$205,382 per year ²²³

215 Information provided to the Commission by DHS, 1 March 2012.

216 State of Victoria, Department of Human Services, *Individual Support Package Unit Price Update 2011–2012*, 2011.

217 Ibid.

218 Respite Alliance Whittlesea and City of Whittlesea, *Respite needs for the City of Whittlesea – background (2011)* 11. These figures exclude support for high/complex needs or behaviours of concern, and the cost of food and utilities.

219 Key informant interview 19, Berry Street.

220 Information provided to the Commission by DHS, 1 March 2012.

221 Based on \$600,000 annual running costs for a new five-bed respite facility, plus \$1.5 million capital costs. Danielle Green MP, above n 212.

222 Ombudsman Victoria, above n 61, 76.

223 Ibid.

Chapter 7: Preventing relinquishment

Investing in families

There was strong consensus that the key to preventing relinquishment was addressing unmet need for a wide range of disability supports. This will require increased resources across the human service system, including investment in workforce, infrastructure and flexible models of support.

Given the significant cost of not investing in services, there was clear support identified in this research for:

- increased resources for facility-based and in-home support and respite so that it can be effective and flexible in response to the family's needs
- significant increases in the supply of key services, including behavioural support, with work also done to ensure consistency in advice and support to families around behaviour management
- increased resources so that Individual Support Packages (ISP) can be accessed, sustained over time and not at risk of reductions in service
- a clear transition strategy for young people entering the adult disability system, in order to remove any need for families to relinquish at 16–17 years in the hope this will ensure their child gets a place in adult supported accommodation
- dedicated resources for sibling support.

The key to preventing relinquishment is addressing unmet need for disability supports.

The Commission welcomes the proposed introduction of a National Disability Insurance Scheme (NDIS), an entitlement-based system, with increased investment in supporting people with disability and providing greater choice. While the NDIS would “not address all the issues within the current system, it would make a significant contribution to addressing some of the current pressure upon parents”.²²⁴

However, the NDIS will not be operational for several years. In the meantime families continue to struggle to stay intact in the face of a disability system that is routinely described as ‘in crisis’.

While resource levels are a matter for government, the Commission is concerned that the ability of people to enjoy their human rights – provided through both domestic and international law – may be compromised if they cannot gain access to the services they need in a timely manner or for the length of time necessary.

It is acknowledged that this requires a significant enhancement in budget allocations to disability supports, on top of the funding increases already announced. This should be seen as an investment in families and young people with disability, particularly as the cost of placing a child in state care so significantly outweighs the cost of investing in prevention.

²²⁴ National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 3.

Planning for prevention

Data collection

Relinquishment is not routinely measured and it remains a hidden problem.

The Department of Human Services (DHS) client management systems – Client Relationship Information System (CRIS) and Client Relationship Information System for Service Providers (CRISSP) – do not readily provide the data required to quantify relinquishment. A complex data extraction is required to determine both the numbers affected and to identify families at risk of relinquishment.

The Children's Court data system is rudimentary and does not provide aggregate data on the prevalence of disability among parents and children subject to court orders.

This absence of data means there is no robust means to measure prevalence, trends or outcomes, which inhibits policy makers from developing effective preventative measures and responses based on sound evidence. It also limits the accuracy or effectiveness of forward planning by limiting relevant trend data.

The capacity of the system to prevent and respond to relinquishment would be significantly improved if the reporting of relinquishment were mandated in the CRIS and CRISSP data systems. Consistent with open government principles, aggregated data on relinquishment should be publicly reported.

Forward planning

The Victorian Government's commitment to developing a whole-of-government Vulnerable Children and Families and Strategy overseen by a Children's Services Committee of Cabinet, as recommended by the Protecting Victoria's Vulnerable Children Inquiry, is an important opportunity to identify and plan for the needs of children with disability and their families, so that the risk of relinquishment is diminished.

The development of the new State Disability Plan provides an opportunity to forecast system demands over the next 10 years in order to guarantee the infrastructure, resources, workforce planning, policy and practice changes necessary to meet the challenges of preventing relinquishment.

The State Disability Plan also provides a platform for delivering on the shared responsibility for the wellbeing of children – including those with disability – across the whole of government, so that existing program and departmental barriers are diminished and systems work in concert to prevent relinquishment.

Dedicated work within DHS to forward plan using the population level trends in disability will also help to target resources. In particular, the emergence of behavioural-related disability among adolescents should be considered in planning improvements to the system.²²⁵

Policy and practice changes needed to make a difference

Risk identification and early intervention

This research found significant consensus about the practice reforms necessary to prevent relinquishment and the harm it causes. Principal among these is a consistent and flexible response to the whole family's needs, with a much stronger emphasis on early intervention.

This is consistent with policy directions across human services and the public health model of protecting children's wellbeing endorsed by Council of Australian Governments (COAG). DHS supported this view, stating:

The preference is to provide effective support as early as possible. Better outcomes can be achieved by targeting the higher end of secondary intervention rather than crisis intervention, that is by giving intensive support at signs of breakdown risk rather than when breakdown is imminent.²²⁶

Establishing a statewide 'red flag' system

A comprehensive system for identifying families at risk of relinquishment is an essential prerequisite for early intervention.

The Commission welcomes the work initiated by disability service networks in north/north west Melbourne to identify triggers for relinquishment, risks linked to the triggers and strategies to target such risks.²²⁷ Using this work as a starting point, a consistent approach to risk identification should be developed by DHS across all regions so that, regardless of where a family lives, a rapid and early response can be put in to place to prevent the family

225 In 2005 it was estimated that there was 33,500 children of school age in the 'difficult behaviour' target group, including 3,500 children with extreme severe difficult behaviour, 5,000 with severe difficult behaviour in danger of progressing to extreme levels, and 25,000 children with emerging behavioural difficulties. See Association for Children with Disability, above n 67, 2.

226 Key information interview 16, Department of Human Services.

227 National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 4.

surrendering care. So that where risk is identified, appropriate and immediate support is provided.

Having a statewide system for risk identification would also assist the department in implementing the recommendations of the Victorian Auditor-General around ensuring a consistent approach to families at risk awaiting approval of an Individual Support Package (ISP).²²⁸

However, it is also important to ensure that any 'red flag' system does not have the unintended consequence of labelling or stigmatising families in need of support. This is reliant on a sensitive and rights-based approach that preserves the reputation of families and focuses on offering proactive support.

Coordinating risk identification with schools and other agencies

A strong theme in the report of the Protecting Victoria's Vulnerable Children Inquiry was the "need for clearer departmental and agency accountability for addressing the needs of vulnerable children, in particular health and education".²²⁹

Clearly, the interaction with education, health and other essential services for children and families requires increased effort. DHS should not be left to carry the load for system failures or lack of resources in other agencies. Nor should families.

This research found a significant link between issues experienced by children and their families in the education system and relinquishment. Families' feelings of not being heard when raising issues with the school, stress factors associated with children's negative experiences in school settings, and inadequate or insensitive responses to requests for supports within schools featured in our case studies.²³⁰

DHS should not be left to carry the load for system failures or lack of resources in other agencies. Nor should families.

Restricting hours of attendance, expulsion or frequent suspension from school could trigger relinquishment. Subject to any privacy issues and with the permission of families, establishing a mechanism for the Department of Education and Early Childhood

²²⁸ Victorian Auditor-General's Office, above n 90, 8.

²²⁹ State of Victoria, Department of Premier and Cabinet, above n 132, Vol 1, xl.

²³⁰ In one case study, however, the school was the primary source of support to the family before and after relinquishment. See case study 4: Janis's story.

Development to alert DHS in these circumstances would be a prudent means of identifying families under pressure and children at risk of relinquishment, and arranging support for them.

The wellbeing of children is a shared responsibility across government. Improving coordination when a child's education is at risk is an important part of delivering on that commitment.

Rapid and flexible responses for families at imminent risk

Intensive support to prevent relinquishment is essential. Such support needs to be creative, quick, responsive and flexible.

The Commission notes that DHS is currently funding a number of Family Coaching pilots in child protection. Although these pilots target families where children are at imminent risk of going into out-of-home care, they have features that could be applied to relinquishment prevention, in particular, the rapid response and wrap-around service elements of the model.

Flexibility around funds so that families can receive the support they need when they need it, alongside dedicated therapeutic and placement prevention resources, are also important elements of this approach.

Services that work

Families want regular, predictable access to ongoing disability supports. This is consistent with family-centred practice that develops an individualised family response.

Making the system more flexible

It is well accepted that child-centred, family-focused practice is critical to building successful outcomes. While this may be a given in policy terms, it is a complex approach that is challenging in practice. While policy makers and practitioners agree that the system should fit the family, rather than the family have to fit the system, there are a range of ways to achieve this.

Removal of rigid eligibility categories was frequently identified as a means of achieving the flexibility that sits at the heart of the individual support ethos. People told us that families need to be given "real choice about the respite services they want to use, rather than being forced to choose what the DHS region they live in supports or funds".²³¹

²³¹ OzChild, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 6.

Several people called for funding rules to be clarified and geographical differences in implementation removed. This includes clarification around Home and Community Care (HACC) eligibility and connections with ISPs, so that people do not lose vital HACC services when they receive an ISP.

System integration

Improved planning and coordination across the system was a constant theme, with less reliance on the lottery of ad hoc professional relationships. Many noted that, if you come from a child's rights perspective, an entitlement should not be dependent on having a worker who has positive networks across agencies and program areas.

The Case Management Action Group operating in the North and West Metropolitan Region was identified as a good model for cooperative work between services and DHS around relinquishment issues.²³²

One family, one plan

Others spoke of going beyond partnerships and collaboration to a significant shift in practice so that 'what works gets done', rather than being tied up in programmatic divisions or lack of clarity about who the client is.

There was significant concern that policy statements around coordination and integration will not deliver results in the absence of clear, practical and specific strategies for how systems fit together to deliver seamless services for families and children with disability.

St Luke's Children, Youth and Family Services has recommended that DHS adopt a principle of 'one family, one plan' across its funded services, and that this be enshrined in legislation.²³³ This principle could be extended to children with disability, and across government, as part of a renewed emphasis upon shared responsibility. The 'One DHS' structural reforms being trialled under the Future State Project are the beginnings of this approach; however, giving 'one family, one plan' legislative force and embedding this principle across all government agencies may be a more decisive means of entrenching integrated practice once and for all.

Innovative care models to prevent relinquishment

Shared care as a model of support

This research identified a number of preventative models of care. The most frequently mentioned by families was shared care, where the child lives at home several days a week and in a supported or family-based placement for the remainder. Of particular concern to families was the recognition that it is quite usual for a child to have many people in their lives, and that this needs to be supported.

Currently, shared care exists in some part under Family Options, and is also used in the child protection out-of-home care system as a means of promoting reunification. However, it is not available on any real scale for the prevention of relinquishment.

Although there are challenges in shared care, the Commission considers that it is worthy of further detailed modelling by DHS as a practical means of providing support to families who are struggling to care full time. Potentially both residential and family-based models could be explored, though each of these creates their own challenges.

In examining options for shared care as a model for prevention services, it is important to differentiate this from the specific cultural meaning 'shared care' has for Aboriginal communities. Complex kinship and community responsibilities are the basis of caring for Aboriginal children in the community, and are based on sharing responsibility for the child. In developing models of shared care – and indeed in the naming of this model – it is important to make this cultural distinction.²³⁴

Specialist respite for children with behaviours of concern

Given that one of the main groups at risk of relinquishment is adolescents with behaviour issues, specialist respite services staffed by people highly skilled in behaviour work is a good model to explore.

One DHS region has recently funded such a model. As this is a new service outcomes are not yet known, but it is a welcome addition to the efforts DHS is making to prevent relinquishment. However, all respite facilities need to be able to look after children who may display difficult behaviours. Workforce training and support is an important means of building this capacity across the system.

²³² National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 4.

²³³ Key informant interview 14, St Luke's Children, Youth and Family Services.

²³⁴ Key informant interview 18, roundtable with members of the Victorian Aboriginal Disability Network.

Behavioural support and early intervention

Ensuring access to quality services for children who display challenging behaviours is a smart way to prevent relinquishment by intervening early and strengthening families. This goes beyond increasing capacity in Behaviour Support Service (BSS) to working up more intensive and longer-lasting interventions. It also requires consistency between funded supports and schools in their approaches to behaviour management.

The Commission notes the positive feedback of case study and key informants regarding the Mansfield Autism School and Travelling Teacher program. The Affirming Families model was also identified as best practice. Unfortunately, all of these programs have limited availability, for example, Affirming Families only operates in one region.²³⁵

Ensuring access to quality services for children who display challenging behaviours is a smart way to prevent relinquishment.

The Commission notes that the Southern Metropolitan Region is funding a new intensive behaviour support service, which is more concentrated than BSS. The Commission understands that, following evaluation, this model may be shared with other regions, and welcomes the initiative.²³⁶

Continuum of care

OzChild has proposed a model continuum of care for families and young people.²³⁷ This has several components, some of which currently exist – for example, Respite Recharge and Family Options – and new elements, including a shared support cluster model for young people 16–25 years.

The continuum of care is a wrap-around approach to cater for the changing needs of the family and young person, with ability to step up the level of support, including accommodation when needed.

While the focus of the OzChild proposal is young people with disability in out-of-home care, the principle of having planned, flexible support and accommodation options to prevent relinquishment is equally sound and worthy of investigation.

Regardless of which models of care are developed, for prevention to work, funding categories that stand in the way of innovative models of care need to end. Removing these barriers to innovation will be an important mechanism for trialling, testing and implementing new ways of supporting families to stay together.

Improving the immediate response

From the perspective of families and advocates, the current response to a child being left at respite or other setting appears ad hoc, inconsistent and unfair. This contributes to poor relationships between DHS and the family, and leaves front-line staff unclear about what they have to do and how they should do it.

A number of suggestions were made to improve how DHS and others agencies respond to relinquishment when it occurs. These include:

- developing a formal policy and work directions for DHS staff and community service organisations to follow when a relinquishment occurs. This could be done as part of the suite of actions already underway through the *Children, Youth and Families and Disability Services Operating Framework*.
- mandating that DHS refer parents to Victoria Legal Aid or other advocates for advice before signing a Child Care Agreement, to ensure all parties understand their rights and responsibilities.
- mandatory reporting of relinquishment in the DHS Incident Reporting System. This would provide a valuable opportunity for DHS to audit incidents and take a thematic approach to improvements. In addition, independent monitoring of these incidents would ensure a higher level of scrutiny and accountability for the steps being taken in relation to individual incidents, and in relation to the themes identified from analysis of incidents.

²³⁵ Affirming Families is run by Melbourne Citymission. It provides a family support worker to come to the home, observe and assist the family to put behaviour strategies in place. It has a maximum caseload of 18 families.

²³⁶ Key informant interview 16, DHS.

²³⁷ OzChild, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) supplementary materials.

Keeping children out of long-term respite

The right to family is at the heart of the rights of the child. If a child cannot live full time with their family then family-based out-of-home care is considered the optimum environment for children. However, this is not always an option when existing programs such as Family Options are oversubscribed and may not always be able to accommodate young people with disability.

Currently there is a significant gap in accommodation and support options for adolescents with significant behavioural issues and other complex needs. These young people can end up living in the limbo of relinquishment.

Ironically, as a desperate measure, these children may be placed in transitional houses even when the clear policy direction is that shared supported accommodation should not be provided to those under 18 years. This is unplanned and unsatisfactory.

The right to family is at the heart of the rights of the child.

The first step in ensuring the child's rights are fulfilled is to shift from ad hoc tactics to a planned approach, which involves parents and children in designing what kind of support will work best for that child. Central to this is developing accommodation options that do not replicate the mistakes of the past, particularly institutions. Mindful that even small-scale settings risk institutionalisation when the autonomy of residents is denied, any accommodation options that are developed to avoid relinquishment must be designed to nurture the child's relationship with their family, promote the child's development and meet their emotional needs.²³⁸ Better still, the focus must be on supporting families so that accommodation options are not required in the first place.

²³⁸ The Commission notes the findings of the New South Wales Law Reform Commission that there should be a hierarchy of preferred support and placement options for children with a disability. This should prioritise in-home support, in-home placement and support with kin or extended family, shared care, family-based long-term care and then support for the child or young person in an intimate residential care environment, with not more than three other children or young people, with consistent adult carers, and in close proximity to the child's or young person's parents and extended family. See chapter 8, para 8.26. <<http://www.lawlink.nsw.gov.au/lrc.nsf/pages/r91sum>> at 9 February 2012.

National Disability Services Victoria concludes:

There is an urgent need to research, trial and evaluate innovative care models, including accommodation support for young people with disability with high and complex support needs whose families cannot manage their care, even with intensive supports in place.²³⁹

During this research, some international models were suggested, including shared support cluster models for 16–25 year olds and a family constellation model.²⁴⁰ All of these are worthy of investigation by government.²⁴¹

Every family is different and so the support required is different too. Some families want assistance in developing their own independent, supported accommodation for their child, close to the family and specifically designed to meet their child's needs; however, health and safety and other regulations create barriers to this. This is an area where creativity, flexibility and a shared purpose between the department and families is needed to find workable solutions:

We want to get him back to Victoria, but this model of care does not exist here. We have been talking to an organisation with a view to buying a property for Richard close to us, so we can replicate the in-home support model that is working so well for Richard there. The only thing that stands in our way is getting through health and safety red tape and reaching agreement with the agency and its staff about the best ways for supporting Richard. The house needs to have particular features; otherwise, they will not allow workers to go in there.

To make things happen, people making decisions need to have the right attitude, the right supports and significant flexibility.²⁴²

²³⁹ National Disability Services Victoria, Submission to Victorian Equal Opportunity and Human Rights Commission (2011) 4.

²⁴⁰ Oz Child, Submission to Victorian Equal Opportunity and Human Rights Commission (2011), supplementary materials.

²⁴¹ The Commission also notes the Mirror Families pilots in Victoria, which aim to provide a lifelong web of supports to children in family-based out-of-home care.

²⁴² Case study 6: Robert's story.

Protecting the rights of children away from home

Community visitor scheme for children in care

As a community, we have a responsibility to make sure that children in out-of-home care or living in respite and transitional houses have the best possible care. Unfortunately, however, there is currently no system for proactive, independent monitoring and inspection of facilities housing relinquished children to make sure their rights are protected.

Visiting by an independent person whose sole interest is what is happening to the child and what the child thinks about what is happening, is a safeguard against oversight, abuse, mistreatment and silencing.²⁴³

This contrasts with the adult system where community visitors routinely visit facilities. Mandated by the *Disability Act 2006*, the community visitor scheme is run by the Office of the Public Advocate (OPA). Community visitors do visit children's respite facilities. They may also visit transitional houses when notified of these premises by DHS. However, in the absence of clear coverage of these premises under the Disability Act, the current system cannot guarantee that every child under 18 years who is residing in a disability setting enjoys the protection of the community visitors scheme.

Child welfare advocates have argued for a community visitor scheme to be established to protect young children living in out-of-home care in Victoria. Similar schemes operate in other states, including Queensland and New South Wales, although each differs in terms of who has responsibility for its delivery.

There are a range of options as to how this could be delivered in Victoria. All would require adequate resourcing to be effective and, as the OPA community visitor scheme is volunteer based, a similar model would be economically efficient.

The preferred option is to establish a community visitor scheme for children and young people in all forms of residential based out-of-home care, including children living in disability settings, such as respite facilities and transitional houses under Child Care Agreements. Such a scheme should be administered by the Office of the Child Safety Commissioner, or any replacement body established by the government to protect the rights of children in response to the recommendations of the Protecting Victoria's Vulnerable Children Inquiry.²⁴⁴

This scheme needs to be accompanied by an enforcement mechanism so that recommendations by the Child Safety Commissioner, or its replacement body, are implemented by out-of-home care or disability placement providers.²⁴⁵ This scheme is the most comprehensive and would require amendments to the *Children, Youth and Families Act 2005* and the *Child Safety and Wellbeing Act 2005*.

To avoid any confusion with the community visitor scheme administered by OPA, which visits adult residential disability accommodation, it may be prudent to give the scheme a title that clearly differentiates it from the OPA scheme.

A second option would be for the Minister for Community Services and Disability to direct the Child Safety Commissioner, or replacement authority, to develop and implement a community visitor scheme only for children with disability in out-of-home care or living in disability settings, in recognition of the particular vulnerability of these children. A similar scheme has just been established in Victorian Youth Justice Centres.

Both options could be complemented with the power for statutory agencies to perform an oversight function. If systemic issues of concern are identified the Commission could review a public authority's programs and practices to determine compatibility with human rights. This would ensure that the full range of human rights is considered and actioned in any review, and would require an amendment to Victoria's Charter of Human Rights and Responsibilities (the Charter).

²⁴³ St Luke's Children, Youth and Family Services, *Ensuring Quality and Community Confidence through the Development of a Community Visiting and Advocacy Service for Children and Young People* (2011) 3.

²⁴⁴ This inquiry recommended the establishment of a new Commission for Children and Young People to report to ministers and parliament on all laws, policies, programs and services that affect the wellbeing of vulnerable children and young people (recommendation 89). State of Victoria, Department of Premier and Cabinet, above n 132, Vol 1, lxiv.

²⁴⁵ Both this option and the second option could include a role for the Disability Services Commissioner and the Public Advocate to be included in a governance or board role for the proposed scheme to provide input on issues relating to providing disability services.

Independent advocates for young people with disability in state care

The right of children and young people to participate in decision making is enshrined in the *Convention on the Rights of the Child* and the *Convention on the Rights of Persons with Disabilities*.²⁴⁶ It is also specifically protected by the Charter. This means that children in state care must have a say in the decisions that affect them, including where they live and how they are treated in care.

Unfortunately, children in care do not have easy access to independent advocates to make sure their voices are heard.²⁴⁷ This is an issue for all children in state care but has particular importance for children with disability, especially when they have communication difficulties.

In Victoria the Youth Disability Advocacy Services receives funding to undertake advocacy for children and young people with disability. It employs a part-time worker to do this important work across the state.²⁴⁸ This contrasts with the United Kingdom, where a dedicated network of independent advocates for young people with disability in care is developing through local authorities and children's organisations.²⁴⁹

Potentially, if a community visitor scheme for children in care were established, this advocacy function could be included. Specialist advocacy skills in working with young people with disability would need to be a feature of those recruited as community visitors.

Engagement with families

A poor relationship between families and service providers, including the DHS and other government departments, often features in relinquishment. Building better relationships through valuing parent knowledge and effort is an important part of preventing relinquishment and responding better if it occurs.

Similarly, respect and mutual learning must underpin relationships with Aboriginal families and communities. Acknowledging the specific cultural impacts of relinquishment on these families and children is the very beginning of this effort.

The Commission welcomes the work of the Disability Services Commissioner in promoting better relationships through its Family Engagement Project and would encourage a focus on the specific needs of families with children under 18 years in that work.²⁵⁰

Valuing parent knowledge and effort is an important part of preventing relinquishment and responding better if it occurs.

The Commission notes the introduction of the *Carers Recognition Act 2012*.²⁵¹ While this legislation does not establish any legal rights, it does set out important principles that disability organisations should apply in their relationship with families and carers.

Consistent with the Bill, and with human rights principles, the Commission encourages the further development of practice methodologies for services and case managers to keep families engaged, to support them before relinquishment and to assist them after relinquishment, in recognition of their role as parents and carers. This work would align closely with the stated policy directions of DHS to ensure that "people are at the centre of everything that we do".²⁵²

²⁴⁶ *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577, art 12 (entered into force 2 September 1990) *International Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 611 UNTS, art 7(3) (entered into force 3 May 2008).

²⁴⁷ The Commission acknowledges that while advocacy is often described as enabling a person to 'have a voice', this conceptualisation is problematic for people who do not use speech to communicate.

²⁴⁸ There is also a network of funded disability advocates across Victoria who work with adults and families, however, these services appear overstretched.

²⁴⁹ The Children's Society, *Someone on our side: Advocacy for disabled children and young people* (2011).

²⁵⁰ "DSC has begun to collect examples of strategies and practices for building and maintaining positive relationships between service providers and the families of the people they support. This project will also seek to contribute to the development of a clear policy and practice framework for the positive engagement of families in disability service provision." Disability Services Commissioner, above n 115, 15.

²⁵¹ The Act received royal assent on 20 March 2012. It requires government and funded agencies to reflect the care relationship principles in the conduct of their business and report annually on the actions they have taken to comply with the principles.

²⁵² State of Victoria, Department of Human Services, above n 18, 18.

Engaging with families in a considered way is particularly important so that the family does not feel like the department is pushing back on them to take their child home unsupported, leading to more trauma and grief for a family already struggling with the consequences of relinquishment.

The Commission welcomes the work of DHS in its Family Decision Making project conducted in 2010–11. In particular we commend its focus on enabling the active inclusion of families in deciding the future for themselves and their child, and in promoting positive relationships between service providers, the department and families. The Commission considers this approach to be consistent with human rights obligations under the Charter, and to be a cost-effective means of promoting healing for families and encouraging reunification.²⁵³ As noted by one family, that project worked “differently from the others and this has made the world of difference to us now we are included back into our child’s life”.²⁵⁴

Responding to trauma

Grief and loss permeated the stories of families who participated in this research.

Regardless of whether families come through the child protection or disability routes into relinquishment, trauma is a significant impact. Families, front-line workers, advocates and organisations all agreed that we need a service system that minimises such trauma and responds better when it occurs. Central to this is providing support to parents, siblings and children to help them recover.

For those families who had been through the Children’s Court, feelings of shame were particularly strong. Many felt that they had no choice but to agree to court orders based on the grounds that they had abandoned or harmed their child because there was no mechanism in the current law that fitted their circumstances.

The Commission notes and supports the previous recommendation of the Victorian Law Reform Commission that the Children, Youth and Families Act be amended to create a ‘no fault ground’ to apply in circumstances such as relinquishment, where there are no other genuine protective concerns present.²⁵⁵ Changing the law in this way

253 This project also had a strong focus on making sure families and disability service providers understood rights and obligations, and that the involvement of child protection staff in facilitating Child Care Agreements was not part of an investigation.

254 Report provided to Commission by DHS, 7 February 2012.

255 Victorian Law Reform Commission, above n 147, 335–336.

would save families the shame and guilt of having a protection order based on a fiction of harm, and recognise that in some circumstances families have no choice but to surrender the day-to-day care of their child.²⁵⁶

Making sure change happens

Throughout this research, it has been clear that the leadership of DHS, front-line workers, community service organisations, the courts, oversight bodies, advocates and support workers all want to see the end of relinquishment. For families and children, that cannot come soon enough. Securing the resources necessary to reduce unmet need, changing policies and practices, and building a more humane response to the terrible dilemma parents face is everybody’s responsibility.

The ideas discussed above and the recommendations that follow require simple and transparent governance arrangements to ensure accountability and to make sure change happens.

These governance arrangements should build on existing structures. For example, within DHS the governance group for the work plan implementing the *Children, Youth and Families and Disability Services Operating Framework* could form a useful platform.²⁵⁷ A simple step could be to extend the role of the Disability Services Commissioner and the Child Safety Commissioner in this group beyond monitoring reports to a more proactive role in priority setting. This could form part of the strengthening of the protocol between the Child Protection Service and Disability Service as recommended by the Protecting Victoria’s Vulnerable Children Inquiry.²⁵⁸

256 The Commission notes that the Protecting Victoria’s Vulnerable Children Inquiry considered the VLRC proposal but did not recommend the Act be amended to provide for a no fault ground, instead they recommended that disability services be provided to prevent children entering out-of-home care. State of Victoria, Department of Premier and Cabinet, above n 132, Vol 2, 339.

257 In 2008, DHS published the *Disability Services Child Protection Protocol*. More recently, DHS has built upon this work by developing an *Integrated Framework for Children and Young People with Disability*. This sets out a number of actions to improve outcomes for children in out-of-home care and to strengthen working relationships between Children, Youth and Family Services (CYFS) and Disability Services.

258 The inquiry recommended “the protocol between statutory child protection and disability services should be strengthened, with more explicit statements around the roles and responsibilities of the different service agencies”. See recommendation 21, State of Victoria, Department of Premier and Cabinet, above n 132, Vol 1, lii.

Further, given the importance of cross-government coordination and shared responsibility for the wellbeing of children, the Children's Services Coordination Board is well placed to bring departmental secretaries from across government together to develop, implement and monitor an action plan to end relinquishment. This action plan could form part of the proposed Vulnerable Children and Families Strategy recommended by the Protecting Victoria's Vulnerable Children Inquiry.²⁵⁹

Recommendations

The Commission acknowledges the complexity of the issues faced by families and children, as well as by front-line workers and policy makers in dealing with relinquishment. To deliver the best possible outcomes the disability and child protection systems require adequate resources, support for staff, flexibility in service delivery, and effective monitoring and accountability, alongside a court and service system that sensitively deals with families in crisis.

The Department of Human Services (DHS) must also be able to rely on other parts of government to fulfil its shared responsibility for the wellbeing of children.

Each of these is a complex issue in itself. Combined they create significant public policy challenges. Nonetheless, the serious breach of rights that relinquishment represents demands urgent attention.

The Commission makes the following recommendations:

Action plan for preventing relinquishment

1. That the Children's Services Coordination Board prioritise the development of a coordinated action plan to prevent relinquishment, as part of the proposed Vulnerable Children and Families Strategy recommended by the Protecting Victoria's Vulnerable Children Inquiry.
2. That this action plan to prevent relinquishment be developed in consultation with relevant oversight bodies, including the Child Safety Commissioner, Disability Services Commissioner and the Victorian Equal Opportunity and Human Rights Commission.
3. That when developed, this action plan be monitored and reported on by the Children's Services Coordination Board to these oversight bodies, and to the proposed Children's Services Committee of Cabinet recommended by the Protecting Victoria's Vulnerable Children Inquiry.

Data collection and reporting

4. That relinquishment be a mandatory reporting item on the Department of Human Services' Client Relationship Information System (CRIS) and the Client Relationship Information System for Service Providers (CRISSP).
5. That relinquishment be a mandatory reporting item on the Department of Human Services Incident Reporting System, and that incident reports be subject to independent monitoring and review by the Disability Services Commissioner, similar to current monitoring of out-of-home care by the Office of the Child Safety Commissioner.
6. That the Secretary of the Department of Human Services publicly report on the number of relinquishments – of children under 18 years, young people aged 18 to 25 years and adults – on an annual basis. This should include a regional breakdown of the data and be published on the department website.
7. That the Children's Court of Victoria be resourced to improve its data collection system so that disability and Indigenous status is included in information available to the court to plan its services.

²⁵⁹ The Commission welcomes the recommendation to develop and implement such a strategy to be overseen by a Cabinet sub-committee – the Children's Services Committee of Cabinet. See recommendations 80 and 83, *Ibid* Vol 1, lxii–lxiii.

Risk identification

8. That the Department of Human Services develop a flag and review system for identifying and acting on applications to the Disability Services Register that have been waiting for three months or more.
9. That the Department of Human Services develop and implement a comprehensive statewide 'red flag' risk identification system for families at risk of relinquishment.
10. That the Department of Education and Early Childhood Development and the Department of Human Services develop a protocol for sharing information regarding children with disability on reduced attendance arrangements, and those excluded or frequently suspended from school. This should be developed in consultation with the Privacy Commissioner.

Prevention

11. That the Department of Human Services scope, trial and evaluate a range of models of care to prevent relinquishment, in consultation with the disability services and out-of-home care sectors, and invite oversight of this project from the Disability Services Commissioner and Child Safety Commissioner. These models include, but are not limited to, shared care and a continuum of care.
12. That the Department of Human Services scope, trial and evaluate a range of behaviour supports to prevent relinquishment, in consultation with, and with the oversight of, the bodies above. These models include, but are not limited to, specialist respite for children with behaviours of concern, intensive behavioural support and the Affirming Families Program.
13. That the Department of Human Services research, trial and evaluate models of accommodation and support for young people with disability who have high and complex needs, and whose families cannot care full time, in consultation with, and with the oversight of, the bodies above.

Early intervention

14. Using the Family Coaching pilots in out-of-home care as a model, that families identified as at risk of relinquishment be provided with a rapid and early response in order to prevent the family surrendering care.
15. That the Department of Human Services and the Department of Education and Early Childhood Development work together to improve consistency in behavioural supports for children with disability.
16. Building on the Disability Services Commissioner Family Engagement Project and the Department of Human Services Family Decision Making project, that the Department of Human Services develop and provide training on practice methodologies for services and case managers working with families at risk of surrendering, or who have proceeded to surrender, the day-to-day care of their child.

Response

17. That the Department of Human Services develop and implement formal work directions and procedures for staff to follow in the event of a relinquishment, in particular for staff working in facility-based respite, and that these work directions be implemented across Victoria.

Supporting families

18. Mindful of the traumatic impact of relinquishment, that the Department of Human Services develop dedicated trauma support services for families and children who have experienced relinquishment.
19. That the Department of Human Services prioritise the development of dedicated supports for siblings of children with disability as part of its commitment to working with the whole family.

Protecting rights

20. That, consistent with the recommendations of the *Report of the Protecting Victoria's Vulnerable Children Inquiry*, and in order to avoid doubt, the *Disability Act 2006* be amended to include a provision specifying that, when delivering services to children, the best interests of the child are paramount and must be observed at all decision-making points. Further, that this provision specifically refer to the right contained in section 17(2) of the Charter of Human Rights and Responsibilities.

21. That the *Children, Youth and Families Act 2005* be amended to instruct Department of Human Services Child Protection Service staff to refer parents to Victoria Legal Aid for advice when requesting that they enter into a Child Care Agreement, and that Victoria Legal Aid be provided with the capacity to provide such advice to parents or carers considering entering into such an agreement.
22. That the *Administering child care agreements in voluntary out-of-home care* handbook be amended to provide that disability service providers also refer parents to Victoria Legal Aid for advice on signing a Child Care Agreement.
23. That the *Children, Youth and Families Act 2005* be amended to provide a 'non-fault' ground for protection orders in circumstances where families are forced to relinquish care due to lack of disability support services for their children.
24. That a community visitor and advocacy scheme for children in out-of-home care be established in Victoria. This scheme should be adequately resourced to include all children on statutory orders or child care agreements living in non-family-based out-of-home care, including children residing in disability settings.
25. That section 41 (a) of the Charter of Human Rights and Responsibilities be amended to provide that statutory agencies performing an oversight function, and who have identified systemic issues of concern, be able to call for the Department of Human Services or other public authority to request that the Victorian Equal Opportunity and Human Rights Commission review programs and practices to determine their compatibility with human rights.

Shared responsibility and accountability

26. Consistent with the recommendations of the Protecting Victoria's Vulnerable Children Inquiry, that the *Disability Services Child Protection Protocol* be reviewed and strengthened
27. That this review include consideration of the governance arrangements for the implementation of the *Children, Youth and Families and Disability Services Operating Framework* and, in particular, that the role of the Disability Services Commissioner and Child Safety Commissioner be strengthened.
28. That, consistent with the findings of the Protecting Victoria's Vulnerable Children Inquiry and mindful of the link between adverse events within the school system and relinquishment, the Department of Education and Early Childhood Development and the Department of Human Services develop a joint protocol to outline processes for implementing shared responsibility for ensuring that children with disability achieve their full educational potential.

Part 2: Case studies

The following case studies relate to incidents that have taken place in recent months and over the past few years. Please note, all names have been changed and dates removed. These stories are related from the perspective of the participant and should be read with that in mind.

All interviewees gave permission to have their stories published and approved the text included in this report.

Case study 1: Erica's story

A few months ago, I had no choice but to place my son Joseph in care. He was 15 years old.

I love my son deeply and have a very strong sense of responsibility. I am his mum and always will be.

Joseph has a moderate intellectual disability and reactive attachment disorder. His disability is a result of abuse and neglect in early childhood and relates to foetal alcohol syndrome.

Joseph first came to live with me when he was three years old. First, I was his foster carer. I adopted him when he was six. It was around that time that he was diagnosed. I have two other sons, one of whom still lives at home.

Joseph went to a special school – they gave it a good shot. The school principal set up an intensive sports program. Joseph did this for three hours every morning. That was the extent of his schooling but it worked for him.

I had some good help from the child psychiatrist at the Community Adolescent Mental Health Service early on. I also did some programs about managing behaviours, including how to restrain Joseph safely. That might sound cruel but as my son grew, safety became a real issue.

I loathed putting Joseph in respite care – he would get very upset and act out. The carers tried hard but were not trained for working with someone with attachment disorder. It was hard to get in – when we did, it would be for short periods and we had to drive miles to get there. It was unreliable and disjointed. This added to the distress.

Having someone take Joseph out and keep him stimulated worked better. Eventually we got five hours of that each weekend. One carer even taught Joe how to play basketball. He loves that now.

We also tried carers coming to the house. However, that does not give you a break because you are always listening out to make sure everything is OK. Joseph needs two carers at all times. I would have preferred part-time out-of-home care that would look after him well – but that never happened. The Department of Human Services (DHS) would just offer more in-home support. It was erratic. At one stage, there were 20 carers on the list.

Things really started to fall apart in 2010 when Joseph was reduced to half a day at school. He was also kicked off the school bus. I tried to keep things together but I was really struggling.

Last year I ended up in hospital in an emergency. I had already started talking to DHS about not being able to care full time. They gave me a funding package. That helped, but the biggest problem was that Joseph was no longer allowed to go to school at all. He had wrecked the school while I was in hospital. Even with that care package, I was getting less time out than when he was going to school. I was on my own.

The next six months were full of meetings. Sometimes there would be 20 people in the room. It was ridiculous. I kept telling them I couldn't cope. I told them that I needed an out-of-home placement. He is still my boy and I love him, but I could not keep looking after him in the home. I cried a lot. But nothing came out of the meetings.

Eventually things cracked wide open. Joseph was running around the house with a knife. My other son had locked himself in the bedroom. Joseph had me pinned in the chair, pulling my hair from behind. This was not the first violence we had experienced.

After things calmed down, I went to the police station. I told them, "I can't do this any more." The police called child protection.

This was not the first time I had called the police. Experience told me that child protection would not do anything about it because it was not a child being hurt, it was me. I knew that to get help I would have to say, "I am going to kill him unless I get some help." So that is what I told them.

Joseph was taken to a residential unit as an emergency placement. They had a lot of trouble with him that night – he was taken to the Child and Adolescent Mental Health Service.

The next day they moved him to another house. He has been there for six months now. He is on his own, with disability agency staff. Another girl moved in, but police took her out after she trashed the place. She is moving in again, I think.

I roster myself on his team every Saturday and take him out. I want to be as involved as possible.

The management of the house does not communicate with me, despite the fact that I am at the house every week. I am never told how he spends his time. I have spoken to management about this and was told, "There is an activity list on the wall." Basically, if I don't ask, I am not told. Some of the carers are good – but things I tell management are not passed on. I am the one who finds recreational outlets in his area and passes the information on to the house. Uptake of these things would make management of him easier but action is slow. I insist on visiting the psychiatrist with staff to keep an eye on the level of medication he is given. This has tripled since he was placed.

I have never been asked for advice on his behaviour management. Nor was his previous psychiatrist. I worry about the standard of staff training in this. They seem trained in caring for physical and intellectual disability not for major behavioural difficulties. That is probably the main reason families end up placing children in out-of-home care and it should be addressed in training.

I want to contribute to costs. I pay for the dentist and all the important things. I receive bills for medications and dressings but I am not told what has happened to warrant these purchases. We were offered \$24,000 a year, and now it is apparently costing \$40,000 a month for his care.

I've got a good disability case manager, who is terrific. It's good that we are on the same track, however, the department doesn't have much to do with it at all – it's the manager of the house that makes all the decisions. Child protection does not come to the care meetings.

I don't know what the future holds for Joseph. I worry about him. He has never forged a bond with anyone. Over the years, when all this was happening, I had planned to care for Joseph until he was an adult but other events overtook us.

My friend, whose daughter had a disability, was looking for a placement when her daughter turned 18 – they still didn't have anything when her daughter died aged 26. I do not want that to happen to my son – that is one of the reasons I had to get him placed now.

I used to be a social worker so I probably know more than most, but even so I find the system difficult to negotiate. All I wanted was reasonable respite or a placement out-of-home for three or four days a week. Currently, the system is all or nothing – that is why parents end up in the nightmare of relinquishment.

Case study 2: Belinda's story

Both my children have disabilities. Heather is 18, her brother Billy is three years younger.

I am a single mum. My husband left when the children were young. I work part time to support us.

Heather has a global motor development delay. Although not classically autistic, she requires cues to focus. She is a large girl and knows when to push boundaries. She requires one-on-one care. Billy mimics Heather's behaviours. He has a similar disability but not as severe. Heather targets Billy, who has always been a gentle boy, but now that puberty has started his behaviours are also becoming more challenging.

Both my children went to a special school. Heather was in a mainstream school for a short period. We had many problems there. Even at the special development school it was a battle to get them to allow her to participate in things like camps and excursions. She was treated differently. That brings out the worst in her behaviours. She goes to a day program now.

Getting help sometimes seems like more trouble than it's worth. There are many people to deal with, even when you have a case manager.

For the Department of Human Services (DHS) to act, it takes a long time, and they have many confusing processes. There are always problems with funding and getting approvals for things. Both my children have been on various packages over the years. Some packages have taken more than two years to sort out. You are approved – but that does not always mean you actually get services. Other crazy things happen, like being approved for special developmental school but not being able to get transport to and from school.

In the last three years in particular, although our needs have increased, there has been a lot of uncertainty about our funding package. We could not get weekend support, when I needed it most. To make matters worse, Home and Community Care (HACC) services have also been withdrawn.

Without a carer I cannot even go to the shops to get milk or bread – it is not safe to leave my two children alone or to take them with me as they might run off. Heather has no road sense and it is dangerous for her. Billy has now started following her – they are both so quick. She will drop to the ground and kick out when she is forced up. It is terrible – for her and for me.

Heather has had a lot of carers. If she is tired or angry she will lash out, as she cannot express herself. If a carer cancels, then it creates problems.

Heather had many incidents with carers, particularly when different carers are rostered. She had three incidents with carers in one week last year. She would target carers daily, especially the ones she didn't know.

About 12 months ago, Heather was really in a bad way. There was a carer – an incident occurred. The carer should have stood up to Heather and made it clear what was not acceptable behaviour. Once Heather had one over on her that was it.

It was a very bad incident. I just cracked at that point – I could not face another day. There did not seem to be an end in sight.

The paediatrician had already told me about relinquishing. As she felt I wouldn't receive the intensive support I required to manage Heather and her brother on a daily basis, she was worried I was going to have a breakdown. That day something just gave way. I remember it was late Friday afternoon, it was a spur of the moment decision but I realised I had no other choice but to relinquish her care as I was starting a new job the next week and I had no carers to help me.

I rang the local DHS office and told them I was bringing Heather. They did not seem to believe me. They told me the office was closing at 5pm and they would not be there. My relationship with that office was pretty poor – I went nevertheless.

We got to DHS just as it closed. Heather was desperate to go to the toilet – what a sight we must have been. I asked the security guard to let us in. I told him to call the police. Somebody, anybody had to give me some help.

The police were helpful but they did not really know what to do. I know the police talked to DHS. I believe they told the police that because it was after hours (it was approximately 5.15 p.m.) they could not do anything and that the police would have to 'babysit' my daughter.

The police contacted the nearest respite centre and I took her there. Luckily, Heather knew that centre. She had no idea I that I had taken this step or what was really going on. I was not allowed to drop off her medication or clothes.

She lived full time at that respite centre for a few days and then she was moved. I was given one hour's notice. I drove immediately to the new house to meet Heather to help her feel more comfortable. The manager did not seem to know my daughter was coming. The problem with that house was that most of the clients were over 40 years. Heather was only 17 years old. They just watched television the whole time but my daughter is very active and needs to participate in many varied activities due to her short attention span. Despite my wishes, Heather was sent there. She stayed three weeks.

Trying to keep Heather in school at the adult respite centre was hard. When at home we had a regular taxi driver, but DHS did not arrange a permanent driver. She played up and attacked the different drivers each day.

More moves followed. She ended up at a young person's respite centre for nine months. That was much better for her age, but she was still living in respite, which is not set up for residential care – DHS did not give them extra help to look after her. She needs one-on-one care.

Heather clashed with other clients at the respite centre. After nine months of living there full time she was evicted. They could not manage her. DHS wanted to move her back to the adult respite centre. I could not let that happen. I brought her home.

When Heather came home, DHS did not offer any additional support. We went back to the same old thing. My case manager is doing their best. This is just as well, as they are trying to reduce my Individual Support Package again. When Heather turned 18, she was supposed to be moving into a Community Residential Unit. I was hopeful that would be a good option for her, but then I found out they wanted to put her in a house with men with very aggressive behaviours. DHS thought that would be a good match but it is not – it will just expose her to behaviours that I do not want her to learn. It just isn't the right the place for her.

I never gave up my daughter, but I just could not do it every day. That is why I took her to DHS and pleaded for help.

I am still fighting for my daughter. I look after her at home, as more and more services refuse to assist us because of safety concerns. I do not know what will happen next but I cannot see an end to this. My son is getting bigger now, too. Without someone to help me and reliable in-home support, I just cannot see how things can get better for my family.

Case study 3: Bridget's story

I relinquished the care of my son Paul last year. It took a long time to get to that decision. I did it in the end because I realised I had reached a brick wall.

I have raised Paul and his older brother on my own for the last 10 years, while holding down a professional job. Paul is 17 and has autism spectrum disorder. I did a lot of work with him when he was very young, so he could toilet, eat well and communicate basic words. My son has fabulous gross motor skills – he is fit, rides a bike, rollerblades and loves his sports.

In recent years, Paul started to climb out the window and wander the neighbourhood while I was sleeping. He has a water obsession and so it could be very dangerous for him. He was never a physical threat to anyone, but he kept putting himself in harm's way. The more I safety-proofed the house, the more I was locking my family and myself away.

I explored the option of him going to a respite facility for a week, and then home for a week. However, by the time Paul's name came up, I was told he was too old for that program.

After 12 months of paperwork, we were approved on the Disability Services Register. I started to get in-home support, so life became all about preparing for carers. I had different people in and out all the time and, even with well-trained carers, Paul would still run away.

I got to the point where I was really under the pump and under pressure. My case manager first suggested relinquishment. I thought that there had to be another way. To give up and beg for help is not my way.

I knew I had to prove to the Department of Human Services (DHS) that the situation had reached a critical stage. I warned them I could not keep going, but they did not take my warning seriously. That was when I knew I had hit the final brick wall – there was no turning back.

When I finally did it – I feared the worst. Paul went to a respite centre for the weekend. I rang them and told them I was relinquishing. They immediately informed the authorities.

I think they took Paul to the DHS office the next day. I rang DHS that evening to find out where my son was. They said Paul was at a secret location and I would find out more in court the next day – they were very hostile.

I could not believe it when they brought Paul to court. He looked so shabby – he still had his pyjama top on. I went and bought him food and clothes to get through the day.

They gave me court papers that said I had abandoned my son. The Magistrate didn't want to know the nitty-gritty, they just wanted to know where DHS would place him.

Initially, child protection called my son's father to see if he would take Paul. His father was aggressive towards the child protection worker. That conversation made them more compassionate towards me and they saw that the father was unwilling to participate in parenting.

Paul was placed in a hotel for a few nights. Then he went to an out-of-home care house – they soon discovered that he needed carers 24/7.

He keeps trying to run away. There have been times where he has run off and his life was in danger. I kept fighting to make them put safety measures in place for him.

Paul gets angry and sad when I leave him after a visit. He turned his room upside down a few times after I left – I had never seen those behaviours before.

They did not want me to visit for a month. I went away, but not seeing Paul was unnatural – for me and for my son. I had to put my foot down – and it was agreed that I could go to the house.

I have been to court several times. I have a lawyer who is very good on child protection and he made sure I kept guardianship and had access to my son. It has cost me a lot of money but it has been worth it, otherwise I just would not have understood what was happening.

Paul is still at the out-of-home care house and comes home to me once a week. It looks like he will soon be moving to a house organised by Disability Services. This has taken some time because child protection didn't seem to know about it at first – the communication between all the offices in DHS can be a real mess.

I am a little worried about who else will be living at the house. They have suggested I buy him furniture and I am getting that all organised for him now. I will have to train the staff about food, diet, fluids and activities so that Paul gets the care he needs.

I am hopeful this will turn out to be a good place for Paul. Nevertheless, I am worried about what will happen when he turns 18, as I have no promises that his new home is permanent.

My experiences with child protection initially were negative, but since then they have been willing to work alongside me. Once Paul moves into his new home, though, their involvement will end.

I have the stamina to keep going to get the best for my son despite all the brick walls. I have never been part of a support group – I did not want to be exposed to other people's fears. I have done it all on my own.

You have to be realistic in the end and say, what is this costing me as a human being to try and maintain this? If I had been able to get shared care, with structured respite, I would have gone on for a lot longer.

Currently, it has to get to breaking point – they wait for it – they listen over the telephone to see if you are at breaking point before they get you the help you need. It was not until I reached crisis point that DHS really started to listen.

Case study 4: Janis's story

My son Jack was born with global developmental delay and epilepsy. He is now 17 years old and a big boy. He goes to special school. It is a wonderful school and the teachers there have been with us all the way. The initial diagnosis was that he would never walk or talk, but he does all those things.

In adolescence, Jack became violent towards his younger brother and my husband. There were quite serious assaults that we could not control. Things were getting really bad at home.

We registered with the Department of Human Services (DHS) and got a case manager. We worked with the case manager for 12 months or more. We received one home visit during that time. I told them we desperately needed help managing Jack's behaviour.

Accessing services is like trying to find your way in a rabbit warren. You get shunted around.

Our paediatrician told us about the BIST program (Behavioural Intervention Support Team) and so both he and I kept asking DHS for that service. It was the only thing we ever asked for. Our case manager refused it straight away. We did not even get to make application. She told us Jack was not eligible because he was under 18. I later found out that this was not the case.

We did get community-based respite one weekend every six weeks. It is a good respite centre. I will not use a department respite house – they are soul destroying. I wouldn't leave my dog there.

Respite wasn't enough because it didn't deal with Jack's behaviours. We got part-funding for a child psychologist but that didn't work either. Things just kept getting worse. My marriage was breaking down under the pressure. I told the case manager, "We are a family in crisis." We were all mentally and physically exhausted.

We desperately needed a break. We were able to get Jack into the respite centre for a couple of weeks so that we could take a holiday. When he came home he assaulted his brother badly.

After two years of trying to get behaviour support, and being told no, we knew we had reached the end. We left Jack at his school in 2011. We rang them and said we were not taking Jack home. The school rang DHS to tell them we had relinquished. I understand that the DHS response was that we would not go through with it. But we did. Jack was put in a respite centre for a few days. The school told me where he was – DHS did not give me any information.

That respite centre was not a good match for Jack, so I worked with the community respite centre he knows to get a space there for him. I organised and paid for this. He is still there six months later.

We had a crisis meeting at the school two weeks after relinquishing because we still didn't know what was going on – nothing seemed to be happening. DHS was at the meeting but we got nowhere. It felt like Disability Services had dumped us, that we were on our own. I kicked and screamed more – I thought, I am going to fight this.

I could not get an advocate – so I went to whoever I could to complain. Disability Services then started offering assistance and funding to take Jack back home but we could not risk this as it is not safe for our other son.

We were so mentally torn because we wanted Jack home but we were concerned for our other son – it was traumatic and awful and cruel that we ended up in this position. Even funding for BIST was offered to us – but for us it was never about the money, it was about getting the supports we needed when we really needed them. If they had invested at the beginning, it would not be potentially costing them hundreds of thousands of dollars now.

I have never signed a written agreement with DHS and our relationship has been soured by our experiences with them.

There does not seem to be accountability in the system. Nor does there seem to be compassion.

I appreciate the stress levels that DHS staff face and that it is a tough job. However, I think it is telling that at no time through this whole situation over two years have we had a case manager that has asked us how we are going. But, for Jack's sake, we want to be allies, not enemies, and so we are trying to build our relationship with the new caseworker.

There is now a chance Jack might move to supported accommodation with some other teenagers. I am worried that this vacancy hasn't been filled because another resident doesn't like change and can become violent. I don't want Jack to be at risk.

So now we are in a strange limbo, trying to find a good solution for Jack and our whole family. We still see so much of him. He comes home on weekends. He asks when he will come home and we tell him that he has a new home now.

One year from now, we hope that Jack will be in independent living with support. We have registered with the Department of Housing and housing associations. Jack is nearly 18 so we need to find a proper home for him.

For any family to go through relinquishment is horrendous. We want him home. I want him home. Nevertheless, it is a family decision: he cannot come home. For me, getting help from other people to care for Jack as he becomes an adult is about broadening our family. Being a good parent is being able to offer a child the things he needs and there can be more than one person who does that – our family just cannot do it on our own.

Case study 5: Elizabeth and Ian's story

Our son Kenton has severe autism and intellectual disability, with behaviours of concern. He has very limited communication skills and is largely non-verbal.

Kenton lived with his two brothers and us until he was 16. For the last 18 months, he has been living in a series of respite centres and Community Residential Units

Our problems really started with school, particularly when Kenton became older.

He went to special school. He hated going there. The bus trip was traumatic for him – although the direct trip took 10 minutes, the bus took over an hour each way. All the stops and starts really upset him. He would self-harm on the bus. These behaviours were fed back to the school by the chaperone, but not to us. We were cut off by the school – that lack of communication by the school set our son up to fail. Even with a helmet to stop injury when he banged his head in distress, he was kicked off the bus.

Kenton can cope with a small class group, but got isolated when his behaviours of concern increased and he was not coping with other classmates. The school was not equipped to work with our son. He required one-on-one care. They could not cope. They started placing him in isolation when he was 15 years old. That made him behave worse. There would be about a three-month window between behaviours of concern starting at school and them manifesting at home.

We sought assistance from Department of Human Services (DHS) with Kenton's behaviour. We looked at a special service that we heard specialised in children with these types of extreme behaviours. At 15 years, Kenton was too old and so ineligible.

A short-term caseworker was allocated. It was like being in a restaurant without a menu; we did not know what our family was entitled to and DHS was not forthcoming in volunteering information. They sent us forms to complete that were long and complicated. Once our application for support was in, we had to ring constantly. We dealt with them honestly, telling them how desperate things were becoming, but they did not understand.

Eventually we got three days' respite once every three months. Because there are so few children's respite centres near our home, we had to travel a bit but it looked like a lifeline had been thrown to us. It took two years to get that respite.

Unfortunately, we rarely got the dates we booked for respite. Kenton did not like it there. There were a few incidents where he got upset and put a hole in the wall. On occasions, they would ring and ask us to pick him up early. That is just the way it was.

By the start of 2010, Kenton's behaviour had really escalated. Apart from some in-home support over Christmas, we had not had respite for nine months. By this stage Kenton had been pulled out of school so Elizabeth was caring 24/7.

We were really looking forward to a visit with family interstate for a few days and had booked Kenton in at the respite centre. When Ian dropped our son at the centre Kenton lashed out at the staff member. Ian had to intervene to protect the carer. We all came home. The family break was not to be.

That same month our Home and Community Care (HACC) day service was cut. The light at the end of the tunnel was closed. Elizabeth spoke to a Behaviour Intervention Support Team worker, explaining that she was desperate. Elizabeth told them she was suicidal and would harm Kenton if we didn't get some help. She did not mean it but it seemed the only way to get them to take action.

The police were called and Elizabeth was assessed at the hospital. The doctor said she was suicidal – we believe he said that so that DHS would help.

Care workers were then provided at home from 9am to 9pm. It was two-to-one support, as females would not be alone with our son. Child protection took the lead but only visited the house once – they would not come back because of staff safety concerns.

Elizabeth was told to leave the house when the carers were in. However, Kenton would not let anyone else care for his personal needs like toileting. Kenton would bite the carers. He started taking all his clothes off and defecating throughout the house.

After seven weeks, the in-home carers were scaled back to seven hours a day. It was no longer a crisis, according to DHS. Child protection did not close the file but said there was no further need for intervention.

It is hard to describe what our home was like during those times – there were holes in walls, with no pictures on walls, and part of the house had to be sealed off as a safe area for Kenton. Our other sons rarely came out of their rooms. It was a nightmare for all us, especially Kenton.

Kenton had never hit his mum before, but then the violence towards her started.

DHS suggested going back to the respite centre. We had big concerns about that. The centre refused to provide staff to care for Kenton – so agency staff were brought in.

Our relationship with DHS was going downhill rapidly. They said we were not in crisis. We asked for adult facilities as we had run out of options in the children's system – they said they would look into it, but nothing happened.

The final straw came just over a year ago. Ian's dad had a stroke and was in palliative care. We asked for emergency care – the case manager told us to "get real". When his granddad died a few weeks later Kenton put his head through the window in distress. It was a terrible time for our whole family.

Trying to deal with grief, Kenton's increased behaviours of concern and unreliable support carers, we reached the end of the line.

Elizabeth packed Kenton's bag, drove him to the DHS office, asked for a case manager and said, "Can you take him please?" She went home and cried herself to sleep in his room.

Child protection came to the house. They told us we had to go to court the next day.

At court an interim accommodation order was agreed. We were not in a fit state to have Kenton home – but we made it clear that we wanted access and to get Kenton back in our care with support. We were not relinquishing our son – we just could not care for him every day unless we got some help that worked.

Disability Services was coordinating the care, while Child Protection did the legalities. It took some time to find where our son was. He had been taken to a house and agency staff had been put in to care for him. He was the only resident there. We understand the staff were initially told to contact the police if we called the house.

He was at that house for two months. We have many concerns about the quality of the care there. Our son had seizures – we believe because they mucked up his medication. When he was sick, no-one told us.

In the meantime the wheels of the court turned. We had to go to various hearings and mediations. Disability Services never came to those mediations. We felt like criminals and bad parents – that is how the system treats you. However, slowly we did start to build a relationship with Child Protection – once they got fully involved we could get things to happen.

To make a final, order the court had to find grounds in the child protection legislation. The only one available was that we had ‘emotionally harmed’ Kenton. That was not true but the system demands a formal ground – so we had no choice. The court said that we should not have ended up there as we had asked for DHS for help.

An order was granted – this maintains our role as guardians and as decision makers. Kenton has now been moved to a new house, which is run by a different organisation. One other person lives there. It is better than the last place and is getting permanent staff, but it still is not a proper home. We had to sort out equipment and try to make it as homely as possible for him. There is a lack of activities for him but the organisation communicates well with us. That is always the hardest part.

He comes home a couple of days a week and every second weekend. No disability support is provided to us when Kenton is here.

Kenton will be 18 by the time this report is published. There is nowhere else for him to go so we expect the house will formally become an adult Community Residential Unit.

It is well known that the only way to get the help required is to relinquish. However, this comes at a terrible cost. We have had a long fight to get DHS to understand that we are not bad parents and did not walk away from our son.

For now – we are slowly rebuilding our lives. Telling our story is part of that.

Case study 6: Robert’s story

My son Richard is now 23 years old. He was 16 when my wife took him to a Department of Human Services (DHS) office and refused to move until we got some help. That was when Richard started his journey of living in respite centres and DHS Community Residential Units. Although we were forced to relinquish our son’s care several years ago – the repercussions for our whole family, including Richard have not ended. This is our story.

Richard was four years old when he was diagnosed with autism and developmental delay. Richard went to a special school for the first year of primary school. Within 12 months he had lost all his language and was in a bad way.

We then enrolled him at the local primary school, which was great. He was welcomed by teachers and friends alike. He had a full-time aide – but they didn’t know much about autism. Richard would be upset and hit out at the other children and the teachers would put him in ‘time out’.

Around that time, I went to a conference on autism in Sydney and learnt about Applied Behaviour Analysis and positive behaviour support. As a family, we then started to use this with Richard. We built our own program based on books that we were able to buy. There was a bit of initial resistance – but the principal was willing to allow the program to run in the school. We used our own money to supplement the program and worked hand-in-hand with the school. By the end of the year, Richard was reading and writing stories; he was, as they said at the school, “a different boy”.

Unfortunately, I then lost my job, which put financial strain on the family. It was not long before the program ended and they went back to the old style of learning. Richard’s behaviour quickly went backwards. By the time he was 11 staff were refusing to work with him.

A psychological assessment was done. The report stated that my son was psychotic – that he had a severe mental illness. The psychologist had no real understanding of autism and its symptoms. However, that report has stuck in the minds of everyone in education – it was the crunch point for all of us. Even though we later obtained expert reports stating that Richard was not psychotic, this report has haunted us, and we believe it led to our son being heavily medicated.

Richard was sent to another special school. The school was more than two hours by bus each way. Richard was made to wear a harness that kept him tied to the seat. There were no toilet stops, no water and no food. His behaviour escalated because the journey was just so traumatic for him.

We were getting increasingly concerned about the side effects of his medication. At one time the introduction of a new medication triggered a period of severe behaviours and what appeared to be psychotic episodes. Richard smashed most of the windows in our house. He would pick at his arms and legs until they bled. He cut his wrist by putting his hand through a broken window. We went to the emergency department of the hospital, but the doctors refused to treat our son – unless we gave him up and left him in their care.

We decided to reduce and then withdraw the medication. The school said we were doing the wrong thing. They felt that everyone was being put at risk. I remember DHS also told me that the severe and brain-damaging side effects of the medication were an acceptable compromise. From then on, the school would only allow Richard to be at school 12 hours per week.

The school called us in to a meeting and said that if Richard hit anyone they would suspend him. The next day he was suspended for three days.

We were given some extra respite because things were getting so tough. Richard went there for a weekend every two months – he came back to us looking like he had been beaten up. He was a mess. He had nightmares for many nights afterwards. Something was definitely wrong in the respite house, but we didn't have any other option.

By the middle of that year, Richard's wellbeing had degenerated significantly – he was a shocking mess. He couldn't understand what was going on. He was banned from children's respite.

A private company provided some in-home respite and some weekends away, which was good, but later that year Richard was banned from the school bus unless he was fully restrained. The school was suspending him very often. The school documented every incident – they claim that there were over 300 incidents. We were made to feel like we were the cause of all of this.

Having Richard out of school made it very difficult for us to manage as my wife couldn't even get a break during the day. By the beginning of 2004, the family found itself with no-one to provide support at home and no access to respite.

The intensity of caring 24/7 was taking its toll on all of us. My wife just said that she could not do it any longer. We were all at risk of being seriously injured – including Richard's siblings – but DHS had said it would not give us anything. Others told us that if we threatened relinquishment we would get what was needed.

Our son being suspended from school again was the tipping point. In desperation, my wife went to the DHS office and said she would not leave until they agreed to give us some help. They offered us 12 weeks' emergency respite. This was to give us some time to sort out other supports. That was all they would offer. We reluctantly accepted it.

There was an agreement drawn up – it was for emergency respite but the house they put Richard in was a dump. It was an old Community Residential Unit. It had been left in state of disrepair after the previous residents moved out. Richard moved there in early 2004. He was the only resident. He was 15. That was the beginning of the end.

A couple of days into his stay, he was badly injured when he smashed through a window that should have been safety-glassed. Within four weeks Richard had attended hospital four times.

He was there for over a year. During that time, there were more than 75 different staff in that house. There was no consistency of care. I believe some staff had turned up to work drunk. I believe our son was abused there.

In 2005, Richard was moved to another house. He was there for nearly five years.

It was a secure facility. Four people lived there. Things were really bad – it was a terrible place. His health deteriorated. He was locked in what staff called "Richard's area". Staff refused to spend time with Richard in that area. In the end he had no contact with other residents apart from through the walls. Two and sometimes three people were required to pass food into his room. His reputation became such that doctors would refuse to treat him – even if he was injured. Once when he hurt his ear, no-one would treat him, and now his ear is permanently disfigured.

In 2009 following a serious incident at the house, the union and WorkSafe became involved. They, without any consultation with us, reached an agreement that led to DHS building what was effectively a cage to ensure that our son could move from the house and the vehicle without any physical contact with staff.

We were caught in a spiral of conflict with the DHS, just as we had been with the school. Complaints did not seem to be getting us anywhere. Seeing Richard in such inhumane conditions took its toll on our whole family, but we were powerless to fix things, as there were no real options available to us.

Our daughter Ella particularly suffered. She was very close to her brother and was deeply affected by what he was going through. She struggled with depression. One day I arrived home to find that she had taken her life.

Sensing my dismay and distress, some friends offered some assistance and with the help of some people in the media, we were able to get a public admission from DHS that what was happening to our son was not good enough.

Some people in another state saw the media story and contacted us. They came and met Richard. Straight away, they clicked with him. They got to the full extent of his extreme behaviours but they were still willing to work with him. They said that it is not his fault, and it is not our fault. Finally, someone understood.

We decided the best thing for Richard would be to go and live with these people. We were concerned that the new agency was unprepared. Nevertheless, we kept coming back to the fact that anything had to be better than what he was experiencing in that DHS house.

It took a few weeks but DHS provided an Individual Support Package to pay for Richard's move interstate and his care there. He moved there early in 2010.

The new service did not give up on Richard even though the first few weeks were bad. They persisted and within a few months, Richard was showing signs of recovery and his mental health had improved.

Richard is now living in his own house (which he rents). He has full-time, one-to-one support. Unbelievably, in the last year there have only been eight incidents, as compared to something happening every day and often several times a day. Most of these incidents are minor – like banging on a staffroom door after having woken up from a nightmare.

Even so, we want to get him back to Victoria, but this model of care does not exist here. We have been talking to an organisation with a view to buying a property for Richard close to us, so we can replicate the in-home support model that is working so well for Richard here. The only thing that stands in our way is getting through health and safety red tape and reaching agreement with the agency and its staff about the best ways for supporting Richard. The house needs to have particular features, otherwise they will not allow workers to go in there.

To make things happen, people making decisions need to have the right attitude, the right supports and significant flexibility. No-one taught us how to manage a child with severe autism and the system just does not seem to know how to respond. That is why Richard ended up without an education, without health care and in such bad houses in DHS care.

Richard's journey is not over yet, and the loss of our daughter just cannot be described in words alone but we keep going.

I saw him two weeks ago. I asked my son, "How are you feeling?" and he said, "I'm happy."

Case study 7: Janeen's story

My son Simon is 20 years old. He has autism spectrum disorder, intellectual disability and a severe behavioural disability. He has always had behavioural problems; however, this worsened as he turned 17.

Services we had come to rely on were withdrawn due to health and safety concerns and property damage – three very big and reputable organisations pulled their services away. Overnight respite was rare and was often cancelled due to lack of vacancies, or we would get a call and have to come and collect our son halfway through due to his behaviours. This left our family with no real support. At present only one respite facility has continued to try and assist us with our son but we cannot leave him more than one or two nights before there is a behaviour episode and we are asked to come and collect him.

We did have access to the Behavioural Intervention Support Team (BIST) but this did not work for us. Not all the workers are experienced with autism and, with 20 or more families on their books, they are massively over-stretched. Besides, when I really needed them, often at night, I just could not contact them, as the service is not available out-of-hours, even by phone.

The behaviour continued to escalate. In frustration, Simon was putting holes in the wall, breaking windows, doors, furniture, hitting out and injuring himself – these episodes could last for hours. It was a major safety issue for Simon – and all of us.

The whole family felt helpless and exhausted. I worry a lot for my daughter who just tries to go on as if everything is perfectly normal. It is so tough on her and she hides her feelings. Disability greatly affects the siblings!

We had been going through hell for over a year. I would never know when I would get the phone call that something had happened to Simon. You end up being hypervigilant – worrying if it will be a good or a bad day, watching your child all the time, or staying next to the phone waiting for a call that something has happened.

I was emailing the Department of Human Service (DHS) and BIST to try and get more help. I could see they were sympathetic but they could not do anything to help.

In the end, I got so desperate that a few months ago, during a behaviour episode – I just placed him in the car and dropped him off at the hospital.

Simon was at the hospital for seven weeks. DHS said they did not have a place to put him in and it would take some time for a place to be made ready.

The hospital restrained Simon day and night (for the first and second day) and provided a one-on-one carer for the first few weeks of his stay. We could not visit him without an outburst of behaviour – he really wanted to come home and could not understand why that was not possible. We were asked to keep our visits to a minimum. I am thankful to the hospital as they tried their best to handle him and it was very difficult for their staff. They saw firsthand our need for support and tried to lobby on our behalf for support with our son.

DHS were always asking if we were going to return him back home, but eventually provided a temporary respite placement for a couple of weeks. There was nowhere else for him to go.

He was heavily sedated both in hospital and at the respite centre. I was very worried about his care. He appeared traumatised and withdrawn.

During this time, we kept talking to DHS to try to find a solution. We wrote to politicians and tried everything we could to get what we needed to bring our son home. Eventually DHS offered a few thousand dollars in funding for specialist behavioural support. Although this only covered half of the amount needed, it was a start!

After nine weeks or so we were able to bring Simon home. I was shocked – he looked like a savage with overgrown hair, long nails and very yellow teeth. They told me no-one could brush his teeth because of health and safety concerns.

We are taking one day at a time. We now have some access to some overnight respite and the new behaviour support person is very good. She comes to our home and works with us all. She is skilling us up in behaviour management. I can call her anytime and she knows her stuff. Having that support available when I need it makes all the difference – she is always on call. If there is a behaviour episode she will come and help the whole family debrief and regroup.

She is now providing her services free of charge, in excess of what DHS had agreed to pay. She said to me, “I can’t give up. You need help.” Nevertheless, I am worried about what will happen in the future as the funding has ended and I still need that support. My caseworker has put in an application for assistance for an extra three months with the behaviour person – I’m waiting to hear if we will get that funding. However, it does not seem right that we have to keep living with that uncertainty. I am relying on her goodwill because the system cannot provide what is needed to keep our family intact.

One of the reasons we had to relinquish was because services were withdrawn just when we needed them, because they could not manage the behaviours. It takes a high level of skill, confidence and ability to read the situation. Respite centre staff need more support from DHS so that they are better able to manage the behaviours that sometimes accompany autism. Otherwise, everyone is set up to fail.

Now he is over 18 Simon is at a day centre. They have almost pulled their services away but I have been working hard with them, and I still am, to keep them involved. If he loses them he will have nothing.

When your child is in distress and is hitting out you need help immediately. If we could have had that support as a constant, our family would not have had to go through the trauma of relinquishment. We got our son back – it’s still challenging, but with support I believe we can overcome. And we will.

Case study 8: Tessa's story

My daughter Emily is 17. She was born with a massive tumour that takes up 10 per cent of her body mass. It places enormous pressure on her spine.

My marriage broke down not long after Emily was born, so I have looked after Emily and her older brother on my own.

Following her diagnosis Emily had major surgery to free up her spinal cord so that she could learn to walk. She was in hospital for months. That has been the pattern all her life – she has had major operations repeatedly. They even tried chemotherapy to shrink the tumour, which I was opposed to due to side effects. Despite all this effort the condition persists.

It is hard to describe the toll having such a medicalised life has on your child and family. We have had our family split up, with my son living on and off with his grandparents, and I have had to give up work many times to care for my daughter. This is tough on any family but is very hard when you are the sole breadwinner.

I have also had a hard time with many doctors who do not seem to want to listen to my views about what is best for Emily. I remember one doctor who was particularly judgemental. She tried to tell me that Emily's disability was attention-seeking behaviour. That is hard to take when your daughter's spine has pretty much collapsed.

One of the biggest problems we have faced is finding and keeping a permanent home. When Emily was quite young we were in public housing near the hospital, as travel from the coast for treatment was just too much. We moved from there into private rental, as we wanted to do better in life. But there are no safeguards in the private rental market and the owner can evict you any time they decide they'd rather live there themselves.

Every time we had to move to another property things got harder. Not only are the rents astronomical, it is impossible to get a place if you have a child with a disability. The majority of homes in this area are inaccessible, and the costs of adapting the property and rectifying it when you move are very high.

When my daughter was in hospital we were evicted. I went to the Department of Human Service (DHS) and told them we were homeless. They told me we were not eligible for public housing because I was working – but that it would be a minimum 12-month wait even if I quit my job and tried to get public housing.

I was also trying to sort out equipment and in-home support for when Emily was eventually discharged. This took about four months' negotiation with DHS. Ironically, they could not do an in-home assessment because we did not have a home. That was the first contact I had with DHS disability services – it was a not a good start but eventually I got some disability funding.

This went on for over a year. We drifted from place to place, trying to get a permanent home. Emily was 14 years old. This was no life for her.

I stayed with friends in the country and tried desperately to find a place for us close to Emily's school, doctors and where her brother could find work. I was commuting to Melbourne for contract work – which I needed to maintain to have any hope of getting a rental property.

At the start of 2009, we were still homeless. I packed up all Emily's equipment, took her to the hospital, and told them I was leaving her there. They tried to refuse me service but I insisted that all our belongings were in the car and I was leaving my child there until we got some help.

I had no choice – it was the only way I was going to get a roof over my child's head.

The hospital social worker organised a three-night stay at a motel. Every few days I had to beg a homelessness charity for help as the emergency accommodation ran out. All this time I was trying to hold down a job in the hope that I might finally get a private rental.

Of course, this was the time of the terrible bushfires. There was no temporary accommodation and massive demand. My son was living at various places, including friends' couches. During the week, my daughter and I were on the homelessness merry-go-round – moving in and out of different temporary accommodation. On the weekends, we would return to our friends in the country.

DHS were not much help. Disability Services said it was a housing issue, and the Office of Housing said it was a disability issue. Eventually Disability Services agreed to release some of Emily's funding for accommodation – but it was a real struggle to get the two sections of the department to sort themselves out.

After a few months I finally got a private rental property. I did this by seeking out real estate agents who were involved in Rotary and the like – I figured they would be more sympathetic. We got the house fitted out to be accessible using our DHS funding. Our things came out of storage. At last, things were looking up.

However, Emily had not been to school consistently for 18 months. Something had happened to the allocation of funding for students with disability in the school. There were no permanent ramps, and the DHS would not fund a motorised scooter for sole use at school. Therefore, the school disability aide had to push Emily around in a wheelchair and carry a portable ramp. Luckily, I have been able to enrol Emily in a different school now and things have improved remarkably.

I have not worked for 18 months and care for Emily full time. As she approaches her eighteenth birthday she has to transition into the adult system for disability and health. Already the signs are not great – she recently went into the adult hospital for an operation, but there was no transition plan from the children's to the adult hospital. I had to walk the scans over from the children's hospital myself.

Our Independent Support Package (ISP) funding has decreased, as I am home to do more of the caring. We are in a precarious financial position. We cannot plan for tomorrow.

I am sure that many of the case studies in this research will talk about the strain families are under when they do not get the support they need. My story is a little different because taking my daughter to the hospital and threatening to leave her there came as a direct consequence of being homeless.

Stable families have different issues from families who are homeless. Every time a family is forced to relocate it is a process of starting over, getting to know people, gaining their trust, forming relationships. This is very difficult to do as a sole parent working and trying to support a child with a disability – there is not much time for socialising. When things go wrong there is no-one to fall back on, and people do not know you well enough to reach out.

Some people are very quick to judge. I believe very strongly that there is an underlying distrust of parents who 'push too hard' or 'make too much noise', but there is no other choice for us. Sole parents are really susceptible because while all of the responsibility falls squarely on us, so does the blame.

Case study 9: Kate's story

My son Graham is five years old. He is now living in out-of-home care in Victoria; however, we are from another state originally.

Graham has a rare genetic condition that creates very significant medical needs. He also has moderate autism and an intellectual disability.

I had no contact with disability services until Graham was three years old. That is when he was formally diagnosed with autism.

Graham was very, very sick and we spent a lot of time at the hospital. When Graham was four we came to Victoria to get specialist medical help. Otherwise, there would have been a 12-month wait to even see a specialist – which would be unbearable for our son who was in pain.

The hospital was great, but the Department of Human Services (DHS) Disability Services were slow to realise we were here. There was no interstate referral between disability services so I presented myself to DHS. I had funding for services from my home state that was supposed to be transferred. However, that did not happen smoothly and it took months to sort out.

My husband and I were in Melbourne alone, with a very sick boy and a small baby, as I had given birth a few months before. I became very depressed and ended up in hospital myself with post-natal depression. I had crumbled under the pressure.

My husband quit his job to look after Graham. He could not cope without me, got depressed and went into hospital himself because he was going under with the stress. He told the hospital he was at the end of his tether and could not cope. The hospital contacted child protection.

I could not leave the hospital because of the program I was in, and nor could my husband. There was no family around to take care of Graham. The Child Protection Service asked me to sign a Child Care Agreement

This agreement was set for two weeks initially, with the option for extension. I was not given the option of legal advice before signing.

For the first two weeks, we did not know where he was placed. I vaguely knew he was somewhere in Melbourne. Eventually I found out the area and was told Graham was with a foster family.

I finally had an access visit five weeks after he was taken into care. Those five weeks were hellish for me but I eventually was discharged from hospital.

Child Protection put us in contact with a family service – but they withdrew, having determined that we didn't have any parenting issues. The Child Care Agreement was stopped and we took our son home.

Shortly afterwards there was a big meeting with DHS and other agencies to plan what should happen next. At the meeting I was very angry with Disability Services because they seemed to be doing things in slow motion.

Disability Services visited once and they said that it could take a few weeks for things to happen. We were then offered in-home respite but what we really needed was out-of-home respite as well.

For a child with autism, out-of-home respite is essential to your sanity. You love them to pieces but you need that time out from the physical behaviours.

Child protection told me that if I didn't accept or comply with the plan they had for my son then reunification would be stopped. What DHS were offering was not addressing the problems that we faced. We needed out-of-home respite and I needed more support for my post-natal depression. However, I accepted the plan of in-home respite (only), as I felt I had no choice.

DHS told us we had a better chance of reunification if we moved back to our home state. So we went back to begin the process of putting things in place for a permanent move.

However, we kept hitting brick walls. In desperation, I went to the hospital to see a social worker. I told her we needed help – otherwise we could not cope. The social worker took this to mean we were going to abandon Graham – which was not the case. She called child protection.

Child protection spoke to us over the telephone and said, "If you abandon your child we will put you in jail." I believe that child protection in our home state then called DHS in Victoria, telling them we were threatening to abandon our child.

The hospital told us they couldn't help because we were formally living in Victoria. So back to Victoria we went – still searching for proper support.

On the day we got back to Victoria, DHS came around to investigate the 'abandonment' accusation. We communicated that because services were so slow to act we did not know what to do. DHS told us to bring our son to the office and without legal advice or advocacy, made us sign a document, which stated that we had, or might, emotionally abuse our son.

Within 24 hours, we were in the Children's Court. The court placed Graham under a temporary accommodation order. He went to a foster family a long way from where we were living.

We were in court for various hearings over the next few months. We had to pay legal fees every time because we were not eligible for legal aid. Our son was not represented in court – he didn't have a lawyer, no-one was protecting his interests.

Eventually, a Custody to Secretary Order was made for 12 months, on the grounds of emotional abuse. This was done by consent – because our savings had run dry and we could not afford legal representation to contest the application.

It broke my heart because we didn't want to lose our son. I remember the Magistrate shook her head in sadness, disbelief and pity.

Graham now lives with a foster family. DHS are more likely to return a child to a family if the parents have extended family support. We made the decision to move back to our home state because DHS told us that it would be better for our child to be in a more supportive environment. However, we are struggling to find the money to fly back to Victoria for access visits.

We are not able to make day-to-day decisions about Graham's care. We are still legal guardians but our parenting rights have been taken away.

I think a mother with post-natal depression should not be treated like this. There are absolutely no reports of us neglecting our son or abusing him – we just needed out-of-home respite when I was sick, that was all.

The impact on our family has been huge. Because Graham has a severe language delay, I do not think DHS understands that he is missing his mum and dad. He has no voice and no-one to advocate for him.

We have been through huge trauma as a family, and each of us tries to deal with it in our own way. No support has been offered to us – we sought support ourselves through private counsellors. The best support we've ever had was from our families.

I feel like I have lost a child. Our aim is to be reunited with Graham no matter what.

I know that all of the DHS workers that dealt with our case acted in good faith and were simply following procedures. I hold no resentment against any of them and I hope to have my son home with me soon.

Case study 10: Kalliana's story

My son Christopher is 16 years old. He has autism spectrum disorder, attention deficit hyperactive disorder, severe language disorder and oppositional defiance disorder. He also has a moderate to severe intellectual disability.

When Chris was diagnosed, I was told he would need care for the rest of his life.

Like any child, there was a mix of good and bad as Chris was growing up. He has some obsessive behaviour, which can be hard to deal with. He exhibited self-mutilation by picking his skin. Sleep has always been a problem.

Because of his language problems, he gets frustrated. He can get aggressive and I do not always know what triggers it.

We got the Behavioural Support Intervention team when he was younger – there was a waiting list, but there is always a waiting list for everything. I did not find them helpful – the workers did not have the experience.

I was fortunate enough to get access to some services, but they are inconsistent so you just end up doing it yourself because you cannot rely on them. I once got a week's respite with a host family when he was young, but that was a one-off.

We had a case manager come on board a few times – but after a while, they would say we were OK, we could manage on our own. It was easier when he was younger, but you still had to tell your story hundreds of times. There were many times I threw up my hands and said, "This isn't working."

I am divorced. I have raised Christopher on my own. I was vocal on getting male role-models and I continued to take him out, even if he had the problem behaviours. We have always been very physically active together – doing sports together, including karate. He plays football and basketball too. Even when the behaviours were most challenging, I always got him out to do things because I wanted him to have those social skills.

A little while back I had a series of falls at work. My health deteriorated and I had a number of operations. Every time I was in hospital it was very difficult. I had gone through the channels, organised carers, sorted time sheets, arranged emergency respite but it was still a mess.

As my health declined, the dynamics at home changed profoundly. Chris would not leave the house and he would not go to school because he wanted to look after me.

His school had a behavioural plan but it was quite a hands-off approach compared to other places. There was an incident where he assaulted another child and he was suspended. I changed schools because I felt the new school would offer more – but that did not work out either so now he is back at his original school, where he is much happier.

I knew adolescence would be difficult. Then my body just gave up – I was on lots of medication myself. I had sustained a significant injury at work, and at the same time my son was getting older and pushing boundaries. It was tough. Services were in and out and very inconsistent. Do not get me wrong – some were good. However, you get to a point where you are organising everything.

During all of this, we received packages – an Independent Support Package and other personal plans. The money was there but not the staff. There was too much inconsistency with the staff, having to train them up – it was exhausting.

Through the whole process there have been mountains of paperwork. You are always negotiating and you only ever get action if there is a crisis. You are always told there is someone worse off than you are. That is the life of a parent of child with disability.

As my health deteriorated I let the ball drop. I got behind with everything and that caused me more stress. Boundaries became even more blurred. It became very hard for both of us. Christopher worried about me.

Things came to a head a few months back. It felt like my head was just hitting against a brick wall. I was going through WorkCover, I was being bullied at work, I was in and out of hospital and I was trying to care for Christopher who had a developmental age of four, yet the body of a young man.

I did not have anything more to give. I was not able to get supports, particularly when I needed them in the morning, and when I did get them they were ineffective. I ended up in hospital again.

I had reached crisis point. Something had to give.

I wanted the best for Christopher and an opportunity for myself to pull everything back into place. I organised an advocate for Christopher. Then I made arrangements.

The advocate took him to the respite house. It took five hours to get him out of the car.

He has been living at the respite centre for nearly a year now.

I have not been to court. I signed a short-term Child Care Agreement. I had to do this for Christopher to be allowed to stay at the respite facility.

He is safe and settled now but, of course, he wants to come home. At first he was not allowed to stay with me home overnight, but more recently he has come home overnight, or for a few nights.

I want him home for good, but I cannot manage that without some more help. I visit him regularly and make sure the respite house keeps up his social and other activities. It is all I can do.

I have been going through a huge grief since Christopher left. I am still going through it. No emotional support was offered; I have sought out my own – I get counselling and see a psychiatrist.

The word 'relinquishment' is vile. You do not want to do it, but you have to do it – you don't have a choice. The family and the child – they both are labelled by relinquishment.

I did everything I could. I do not want to lose my son – but that is how it feels in more than one way.

Case study 11: Sandra and Tom's story

We have four children. Our eldest daughter Nell has Down syndrome. Until she was 16 we cared for her on our own. In that time we did not have services for her, apart from a day trip every six months or so. Nell went to special school, which she enjoyed. The school was very supportive of us.

We were a family that never complained. We felt there was a stigma around asking for help so we remained polite and waited our turn. However, our turn for services never really came. All this time the pressure was building on our family, especially as our other children grew older and needed support to navigate the waters of adolescence.

We were both holding down full-time jobs and found it hard to make ends meet financially – we desperately needed a break so we could recharge and keep going.

Nell's name was down with various support services. We were told she was not eligible for a Department of Human Services (DHS) package because we were not disadvantaged enough. Local government Home and Community Care services were then suggested to us as a last resort. They were quite good at linking us with a few services but we never had enough support.

Eventually Nell was given a case manager. We then received respite for one weekend every six weeks. We soon learned that Nell's respite would be cancelled because other children who had been relinquished were in the respite centre so no vacancies were available. When she did attend respite, Nell did not settle well and began displaying behaviours that led the respite centre to call us and make us take her home. These behaviours, which had never previously occurred with us, then started to happen at home.

Our family was exhausted.

As Nell's 18th birthday approached we were informed that all her current respite would cease. Nell was to transfer into the adult disability system. They told us that Nell's needs would be assessed in light of the priorities of the adult respite service. They would not give us any firm dates for future respite. To us, that meant that unless the family faced a crisis that all could see, we would be overlooked again.

Everything unravelled after that. Just before Christmas we were told this was Nell's last respite – they wouldn't answer our questions about what would happen next. We knew the adult system was clogged and all our existing supports were about to be removed. We had to do something drastic to get Nell the services she and our family needed.

We decided to relinquish the day-to-day care of Nell before she turned 18 so she had some chance of getting adult services. We told no-one, not even our daughters. We will never forget the day we packed Nell's bag for the final time, knowing she would not be coming home. It was the hardest thing we ever did but we had no choice.

We rang the respite service and told them that we would not be collecting Nell. Things moved very quickly after that.

We were called to an urgent meeting with several DHS people. It felt like an interrogation, they put enormous pressure on us to pick Nell up. They told us that they had nowhere to put Nell and everyday she stayed in the respite house was taking from other families who were in more need than we were.

More meetings and pressure followed. They told us Nell would be made a state ward, that we would lose our daughter and have no rights. We were not given an option to seek legal advice.

All we wanted was services to buffer us and then we would be happy to bring Nell home, but DHS did not seem to see this.

Eventually we found a great advocate who then attended all the meetings with DHS and supported us throughout the process. We found out about this advocate through our doctor.

For the next six months Nell was moved from respite facility to respite facility. We felt DHS was using this as a tactic because they knew how distressing this was for our daughter and for us. They failed to notice our family was already broken and we could not take Nell back.

Nell was taken out of school by DHS as she moved from place to place, and she approached her eighteenth birthday. Nell was placed in a privately run respite centre quite a long way from us. She also attended a day centre. The respite house kept sending us the bills, which we could not afford. Eventually DHS paid the bills following pressure from our advocate.

At the last hour DHS decided to offer us a package of care, including respite. However, this package was only until the end of the financial year. We were scared that if we accepted the offer we would be back in the same position in six months' time.

The whole process to find a permanent home for Nell took about 12 months. By this stage she was 18 and was placed in an adult Community Residential Unit. Her original room was very small, more like a study, and she shared the house with much older women. The property has been improved and Nell has stability, but there are no young women of her age at the house.

Nell has lived there for several years. It is her home now. We see her all the time and Nell is close to her siblings. It has worked out OK for our daughter in the end, but it has been a hard journey for our whole family. It is not a journey we would wish on anybody.

We were numb for the first 12 months until Nell was placed in the Community Residential Unit. Once we knew our daughter was settled we crashed and all the trauma and grief came out. Sandra had counselling but Tom had no support.

We still feel the repercussions in the attitudes of some disability staff. We were made to feel excluded then. There is still a perception that once families relinquish their child they should not have a say, and so we are not included in meetings around Nell's life plan. We still feel the stigma and powerlessness of relinquishment.

There is no support for families who find themselves no longer able to care full time for their children. Being a carer is lonely and no-one can understand how it feels to reach the end of the road. We believe the department could have responded to our plight much more sensitively and recognised that we were going through trauma, guilt and shame. If we could have worked together to find a solution, that would have been much better than going into 'damage control'. Even better, if we had been given the help we needed earlier on the whole thing may have been prevented.

Case study 12: William's story

My son James has profound physical and intellectual disabilities caused by a rare genetic condition. He cannot talk or walk, has poor motor skills and a severe developmental delay. He has epileptic seizures and significant sleep disturbances.

Now 10 years old, James loves water and communicates with his emotions and via smiles and through his eyes. He goes to specialist school. While my son is a happy child, I worry for the future and what will happen when I am not around or can't help my son – I don't feel I can trust the system to ensure my son has all the things he needs.

For his first five years, James didn't sleep during the night, and nor did we. My wife and I worked part time so we could share the care of our son. Given the level of care needed, it was not possible for either of us to work full time. Nor was it emotionally possible.

We went through a lot of grief coming to terms with having a child with such significant disability, and the stigma that is still attached to disability. The community still does not understand that difference has a place in our community.

At the beginning of 2010, my son's health stabilised and so I took a full-time job, as we needed the money and it meant I would be home on the weekends. This meant my wife was caring for him more.

As a carer, you must contend with a multitude of services, access to funding, trying to provide for a child with multiple and complex needs. There is a huge amount of physical and emotional stress being a carer, and it can isolate you. After a while you forget to look after your own health – you sacrifice yourself to look after your child. That is what happened to my wife. She ended up in hospital.

I then had to give up work so I could care for James full time and also care for my wife. When she was discharged from hospital I was very worried about her coming home to the same issues that had caused her illness in the first place. I tried to talk to the hospital staff about this – but they put nothing in place for her upon discharge even though a psychiatrist had said the home environment was untenable.

I tried to get funding from the Department of Human Services (DHS) for some additional support in the home. I was promised two weeks' funding, then six weeks, but it turned out this had not been approved because the person processing it only worked part time. As a stopgap, they gave us three days' funding.

We then got six weeks' funding and waited to hear if our application for an Independent Support Package (ISP) would be approved. As I feared, the six weeks' funding expired the week before Christmas and the package was still not yet approved. We were told our funding would end in a week. We had no help over Christmas and no light at the end of the tunnel to cling to.

While we fought for funding we had to go to a lot of meetings, but just couldn't seem to get what we needed. In these very desperate times it seems that the system's response to a crisis is not to do very much, but to stall – it is a cruel indifference to a family's plight. Eventually my wife ended up back in hospital, and my health was starting to fail as well. I was admitted to the Cardiac ward at Royal Melbourne Hospital.

James was put into emergency respite for about six weeks as our family crumbled under the pressure.

Throughout all this, there was no coordination between DHS disability services and the health service. We tried to arrange a meeting with my wife's psychiatrist, but DHS refused to attend, saying it had nothing to do with them.

The drip, drip of funding went on for several months. This trickle of funding makes things uncertain and this uncertainty, when you are in desperate need of assistance, is very frustrating and stressful. That is what disables you as a parent.

Finally, with legal help, we got a package. This expires in June 2012. We don't know what will happen then.

I will have to start asking for funding again early in the new year. Although DHS has said we will not go unfunded, I just can't afford to put trust in what is said. I can only measure assurance and trust on actions – history has robbed me of any trust.

Our family has had to fight so hard for everything – for funding for aids and equipment, for respite, for carers, etc. – when all of this should be part of the support and assistance that is readily provided for my son. For us these are essential services.

We currently get support from in-home carers but it seems we have a different person each day, which impacts negatively on my son. We access respite when we can, but the quality of respite services can be very poor, especially for a child with such significant medical and care needs. Care plans and medical instructions are not followed properly. In my own case I have seen respite workers fail to recognise when my son is having a seizure – they just aren't trained well enough. I was told by the staff, "We don't recognise those as seizures." And I felt that my concerns were just being ignored at my son's expense.

People have told me I should just give up, but I refuse to do so. Our family has been through enormous trauma in order to avoid relinquishing our son, and it has come at significant cost to our health. It does not need to be this hard and the system needs to change if children with disability and their families are to get the care and attention that we deserve as human beings.

Case study 13: Karen's story

My son Dominic is now 21. He has autism, Tourette syndrome and severe anxiety disorder. When he was 14 he moved into a house run by a disability organisation. It was a hard thing for our family – but we had to do it.

When Dominic was about four years old, a visiting kinder teacher would come to the house. She would sit and watch him play. She told me about a local autism organisation and gave me their details. I said, "You think he is autistic?"

That was the best thing that ever happened for us. That organisation is brilliant. They have provided lots of practical help along the way and they get where we are coming from. I would be lost without them.

I had no access to services through the Department of Human Services (DHS) because he was high functioning. We had about six hours a month respite through the local council Home and Community Care (HACC) service. We also accessed respite through the autism organisation. Because of my daughter we had to separate our family with outings and things. Dominic would destroy things. If we went to the park he would be behind the toilets, tearing out the sewerage pipe.

Dominic had a hard time at school. He went to special school for most of primary but then had to go to a mainstream secondary school. Dominic does not have a good understanding of language or perception of what people are saying. If someone says, "It's time to finish on the computers," he would react badly. He cut through all the computer cords because to just finish is like being punished. Dominic would need a timeframe to follow before they were turned off. People have to be very specific in the way they speak to him.

He gets angry and then holds onto it. You might think it is over but he retaliates days later. He lashes out and can be very violent.

He was suspended frequently towards the end of primary school when we were trying out a mainstream school, but he saw the term out. For high school he had to go to a mainstream school. Even with an integration aide who knew him the behaviours still got out of hand. He hit the aide about three times. The principal was on the phone to me every second day.

I was still looking for answers and for things we could do. I was lucky enough to be able to get him into a residential school for children with autism for one term. They still had issues but it was a good chunk of respite for our family. He only came home once and we visited a couple of times. It was good for our family to have a big break so we could recharge and regroup.

That was only for one term. Dominic was really struggling back at mainstream high school – things were getting out of hand.

The residential school placement gave us access to a 'travelling teacher'. She would come to our house and live with us for two or three days. I am just lucky that I pursued it as there is only one travelling teacher per region. We had the same teacher each time and she was brilliant. She would stay for a few days, watch the family, and interact. She saw the worst of the worst, when things really exploded.

I took him out of high school in 2004. I thought, "Enough: too many people are getting hurt." Funnily enough, I did not get any phone calls about him not being at school.

He was at home full time from then on – that is when his behaviour really escalated. If I went out, he would get hand shears and cut all the cords on the blinds in the house. He would try to get out of the car when it was moving. My daughter would lock herself in her room for some peace. She could not leave anything out that she loved because Dominic would destroy it. He did not do this out of malice, he just could not help himself.

Dominic hit me a few times both at home and at the shops. Once he found a padlock and threw it at my head. I had concussion. He was getting bigger and stronger. He would flip over the bed, rip off a bed slat and come at me with it. I had to lock him in his room – for my safety, for his safety.

It was no life for anyone. I was turning into someone I was not. I called the police but nobody could help me. The police came around and the GP came around. The sergeant said, "There is nothing we can really do. All we can do is fill out an intervention order."

I was referred to the Community Adolescent Mental Health Service. I am sorry to say it but they really were not any help. I am not someone who usually has a problem talking to people, but they just lay on the blame and I would never go to them again. I would ring them and beg them, saying, "Something has to happen." But it never did.

His behaviour was escalating in the run-up to Christmas. The police said they would write a letter on our behalf, saying, "Someone needs to help you." One day I walked into his room and Dominic was naked, there was glass on the floor and he came at me. I grabbed the mattress to protect myself. Dominic sat there and cried. I thought, My son is falling apart.

I called the adolescent mental health unit repeatedly – I kept ringing them directly. They said they didn't take any admissions at Christmas. I called everyone, even child protection at DHS. I was frightened for myself and my daughter. They said, "Sorry we cannot help you with a child like that," I hung up but I got the person's name. I kept details of all conversations. Then I went to every politician/minister I thought could help.

I thought I would have a nervous breakdown, I was emotionally and physically exhausted. He got into that unit in the new year. They started him on new medication. He was discharged a month later.

After hospital he stayed in the family home a few months. He had mellowed a bit but it was still difficult. Mid-2005 I got the call from the organisation that had supported our family for years – they had an opening in a house. The CEO said, "It's not the best place for Dominic, but it's a start."

It was like a group home, owned by DHS. There were four boys living there. Dominic was 14, the others were about 17–18. Things started badly. Dominic totalled the house. He pulled down the brick BBQ by hand, pulled out the Hills hoist, curtains were thrown into neighbours' yards. He abused the neighbours and, understandably, they were not impressed.

A few months later DHS called and said they had a place outside town. It was called a transitional house – the idea was that, when ready, residents would have a slow integration into the community. My son has been there for six years. It is on five or more acres and has two units with staff quarters in between. The staff there are brilliant – they love Dominic.

Eventually he went back to high school, which was allocated the top level of funding from education to support my son. I do not know how families can do it if they aren't able to keep records or speak to people. I spoke to the school and said, "Female integration aides are out; classrooms are out. He can't cope because he doesn't have the social understanding." They understood and recognised this and persevered with him.

I was told of someone interested in working with children with disabilities. Somehow the school found him first, but this was the best outcome for him, them and us. With this support worker things finally fell into place because the aide thought outside the box. I am so grateful to him. We still had huge issues but he was at school. My son even finished Year 12 – not the curriculum part of education but he was there.

I have stepped back now because he is an adult. He is vocal and he can speak for himself. He can discuss with workers what he wants. If there is anything serious, they will let me know and then I can get involved. He rings me every night on the dot of 5 pm.

Dominic feels that now he is an adult he should not see his family so much. That would upset many people, but that is what he wants – he is a young man now. He has his goals and dreams. He wants to move to Melbourne.

I never 'relinquished' my son. I sought a better life for him and for us. I know people who have taken their children to respite and walked away because they had no choice. Parents are not giving up on their children; they are seeking out a safe place for them. I believe my son would have ended up in the juvenile justice system if nothing had changed.

The people at my local autism organisation were great. As a parent you are always being judged. I was always putting on a brave face with everybody, except with the workers there. That organisation never judged me. They understood what I was saying and they did not minimise it. Even to this day, I am in contact with them. They changed my life.

Case study 14: A respite worker's story

I have worked in a Department of Human Services (DHS) respite centre for over a decade. I have had various jobs at the centre, including being a house supervisor and a direct care worker.

Our facility cares for children aged from 6–18 years of age with varying degrees of intellectual disabilities. About 50 families use our service, where we provide short-term, planned overnight respite.

Like other respite houses in the region we have a very dedicated and stable staffing team. Almost all of the children who access this facility enjoy coming and are well cared for. We have a regular pool of reliable casual staff to call on when shifts require covering and we rarely need to use agency staff to cover shifts.

The term 'temporary resident' is a term used by DHS to identify a child who has been relinquished into the care of DHS and is residing in a respite facility. Most come into the centre as an emergency placement and after about two weeks they become known as temporary residents.

One of the more recent temporary residents started living here full time as a nine-year-old and stayed for over two years – that's almost a quarter of their life spent in a respite facility.

These children are left in limbo until a more suitable placement can be found. It is sometimes difficult and unsettling for these children to live in an environment that is set up to provide short-term planned respite. They often have to share the facility with up to 28 different children (many of whom they are not compatible with) each week.

Living in a respite facility is particularly hard for children with autism spectrum disorder, since sometimes the need for routine and a quiet and settled environment cannot be met in a respite facility.

Sometimes the child is able to return to the family home with a range of added supports and services. Other times a foster family (Family Options placement) is found. However, these placements are pretty rare for children with intellectual disability. More often than not the child is moved into a Community Residential Unit.

The relinquishment of children into respite centres is not new. In the many years I have worked at this facility there has almost always been one temporary resident and, on a few occasions, two temporary residents in this predicament. It is a pattern that is found across all the respite facilities in our region. A few years ago one of the respite houses ceased to operate as a respite facility for some time because all of the beds were used to house temporary residents.

More often than not we are given no more than a couple of days' notice that a temporary resident will be residing at the facility. Often families with planned respite bookings are cancelled to accommodate this placement.

I have had experiences where the family has relinquished their child to the centre and found out later that the case manager, respite bookings coordinator and other DHS staff were all aware of the mother's intentions not to collect her child three days prior to it happening.

It is left to the respite facility staff to normalise the situation for the child as much as possible, as well as doing all the paperwork associated for making sure a proper care plan is put in place. There are ongoing meetings with case management, parents and schools, appointments with health professionals, transport arrangements, medication requirements, clothes shopping, recreation and leisure activities, and key worker reports to name just a few tasks. All of these extra responsibilities are absorbed into our core roster without any additional hours, funding or resources provided by DHS. Staff do the best they can; however, it is difficult to meet more than the daily care needs of temporary residents and the extra workload does impact on the running of the respite facility.

Despite relinquishment being a constant in the life of most respite facilities, in this region there are no specific DHS policies, procedures or guidelines on what the roles and responsibilities are of case managers, respite house supervisors, client key workers and care staff in relation to meeting the initial and ongoing needs of a child who has been relinquished. Key documents such as the Centralised Respite System Business Rules are silent on relinquishment and what should be done if a child is not collected from respite as planned. We are all working in the dark, even though relinquishment is a fact of life in our current system.

I have raised this again and again with my superiors but still nothing is put in place to guide staff on how best to manage what is a traumatic and difficult time for these children and their families. Surely we can do better.

Case study 15: A friend and carer's story

I met Amelia nine years ago through my daughter's school.

Amelia has four children. Two have diagnosed disabilities. Both are now teenagers.

Both have attention deficit hyperactive disorder. Her son also has Asperger's syndrome and poor eyesight. Her daughter, Rebecca, has separation anxiety and oppositional defiance disorder. A younger child is a bit behind on the learning curve and has signs of obsessive-compulsive disorder. At this point, his disabilities are not as severe as the older children's are.

Amelia is a single parent. Rebecca's father had drug problems. Child protection got involved and the two children were out of Amelia's care for a while. I think that is what started Rebecca's separation anxiety. If she is not physically with her mum, she will call her 15 times a day.

Amelia's second partner was violent. She had a really rough time of it and child protection got involved again. Once he was removed, she was on her own with four kids, struggling to pay the bills, the mortgage. Amelia pays for everything – medication, psychiatrist visits and the like.

She does shiftwork to get by. It is a lot of strain to be under but at least she and the kids are safe now. Amelia is certainly under a lot of stress and struggles to cope, especially since Rebecca has become a teenager and her behaviours have gotten more extreme.

Rebecca has learnt to use violence as a way to get the attention she wants. There has been a lot of trouble of school. It is hard to tell what trouble she was getting into and whether it was bullying or whether she was instigating it. The fact of the matter is that other students taunt her until she reacts and lashes out.

Rebecca fell further and further behind at school. She stopped going halfway through year 10. No-one from the school seemed to notice or care. Her brother is out of school now as well.

There is no-one to help Amelia address Rebecca's behaviour. Amelia takes anti-depressants, which is helping, but not a lot. She finds it very difficult to cope, especially because, as the children cannot be left alone, there is no respite. She has limited parenting skills, but is doing the best she can.

From where I sit, Amelia is not getting much help from Disability Services, and the coordination with child protection doesn't work very well. Generally, the view from the Department of Human Services (DHS) is that Amelia has to ring Disability Services for help

– child protection does not make that contact for her even though they are supposed to be managing the case. I do not think she has disability funding or a support package. As far as I know, she has been referred to Autism Victoria, that is it.

Amelia gets in trouble from child protection for being late for appointments – they seem to forget that she works shiftwork and has four kids to look after. All the family services they have been offered are during the day, often when Amelia has to work. There is no flexibility about when services are available – you just have to fit in with them.

I know Amelia has asked DHS to take Rebecca at least twice. She has done this because she cannot cope – the children are big and strong, they do not take their medication and the pressure overwhelms her.

Everyone is working at cross-purposes. This undermines Amelia's role as a mum – which Rebecca picks up and this leads to even more problem behaviour. It is a vicious cycle that Amelia can't break without proper help.

I do the best I can to help Amelia. I drive the kids to sport, walk them to school every day, take them on holidays. I talk to Amelia almost daily and try to help financially when I can. Supporting Amelia has had a significant impact on my family. I feel caught between a rock and a hard place. I cannot step away, because I'm worried for the children and for my friend. You get to the point where you do not know what to do.

I wanted to tell this story because it's important to recognise that when the system does not work it not only affects the family and the children, it affects all the people around them. I have tried hard to fill in the gaps from a system that cannot seem to meet the needs of a family under enormous pressure. If I am not there, who will be?

Case study 16: A foster mum's story

Elliot was surrendered by his parents when he was three months old, along with his twin brother.

As a baby, Elliot suffered a brain infarct which resulted in cerebral palsy. He has a range of other significant disabilities, including development delay, blindness and scoliosis. He has gut syndrome so ileostomy bags are required.

Elliot was in the hospital for that whole time before he came to live with me when he was three. I had been approached previously about fostering him. However, at that time I was already fostering a child with disability and wanted to see that through.

In the beginning Elliot screamed constantly. It lasted for the first three years. I remember the first night Elliot settled properly – my husband passed away that night. It was as if Elliot knew to sleep through the night to help me. That is the type of special bond we have. I love him dearly.

Elliot is now nine years old. He is well adjusted and is a happy boy. His good health is down to my taking care. He goes to school and loves the social aspect of this. It also provides a good break for me. Everybody needs that.

As Elliot's foster mum, I get respite once every six weeks. Foster carers don't get a lot of financial and practical support. We face the same challenges sorting out packages, getting equipment and support as anyone else. However, the rewards of fostering a child like Elliot are immense – you certainly don't do it for the money!

We have a loving family unit. I have another foster child. I have a permanent care order for him, with a succession plan for my birth children to care for him when I die. I do not have a permanent care order for Elliot as his care needs are much higher and I can't ask my children to take that over.

I am worried what will happen to Elliot in the future. I am 60 now. I was sick recently but could not go to hospital immediately because I was caring for Elliot. The next day, Elliot went to an emergency carer for four nights while I was admitted. He also went to a respite facility but this was not as good, as Elliot has high-level medical needs and the general respite staff are challenged by that.

The foster agency was then able to organise accommodation at a specialist placement who have highly trained staff. The Department of Human Services (DHS) paid for this in addition to his Individual Support Package. Nevertheless, it has got me thinking – what will happen to Elliot if anything happens to me?

Foster families for children with disability are rare. I am really worried that the only option will be a nursing home because of his high medical needs – I could not bear that. It would be inhumane for such a young boy to end up in a place like that.

I do not judge Elliot's birth parents or other families that feel they have no other choice but to relinquish. You have to think of the whole family, including other children. I recognise that this is a difficult choice – but it in all that sadness, it gives me an opportunity to care for children with disability,

I love caring for Elliot. I have suffered the loss of a child, and had another child who was very seriously ill. I made a deal to give something back and I am honouring that commitment through him.

Part 3: The legal and policy context

Human rights law and relinquishment

The Equal Opportunity Act

Discrimination based on personal attributes, including age, is unlawful under the *Equal Opportunity Act 2010*.²⁶⁰ The Act also protects people from discrimination based on disability.²⁶¹

These provisions protect children and families from discrimination in areas of public life such as education, health, accommodation and service delivery – which includes family services, out-of-home care, child protection and disability services.

The Equal Opportunity Act requires organisations, including disability and child protection services to take a proactive approach to preventing discrimination. This positive duty, which commenced in August 2011, requires services to take reasonable and proportionate measures to eliminate discrimination as far as possible.²⁶²

This includes taking steps to address the structural barriers children with disability and their families face in accessing services, and paying regard to particularly vulnerable groups who may face multiple disadvantages, such as Aboriginal children with disability.

²⁶⁰ *Equal Opportunity Act 2010* s 6.

²⁶¹ *Equal Opportunity Act 2010* s 6.

²⁶² *Equal Opportunity Act 2010* s 15.

The Charter of Human Rights and Responsibilities

In Victoria, public authorities are obliged to protect and promote rights protected under the Charter of Human Rights and Responsibilities (the Charter).²⁶³ A 'public authority' includes the Department of Human Services (DHS) and organisations that undertake public functions on its behalf, such as out-of-home care and disability service providers.²⁶⁴ This means that services are legally obliged to observe the human rights of children and families with whom they have contact.²⁶⁵

Children are given specific human rights under the Charter. These include:

Recognition and equality before the law: which protects the right of all Victorians to enjoy their human rights free from discrimination.²⁶⁶

²⁶³ *Charter of Human Rights and Responsibilities Act 2006* s 38(1). However, this does not apply if, as a result of a Commonwealth or state statutory provision or otherwise under law, the public authority could not reasonably have acted differently or made a different decision. *Charter of Human Rights and Responsibilities Act 2006* s 38(2).

²⁶⁴ *Charter of Human Rights and Responsibilities Act 2006*, s 4(1)(a), (c).

²⁶⁵ *Charter of Human Rights and Responsibilities Act 2006* s 38(1). However, this provision does not apply if, as a result of a Commonwealth or state statutory provision or otherwise under law, the public authority could not reasonably have acted differently or made a different decision. *Charter of Human Rights and Responsibilities Act 2006* s 38(2).

²⁶⁶ *Charter of Human Rights and Responsibilities Act 2006* s 8. This is reinforced by the right, without discrimination, of every child to such protection as is in his or her best interests contained in section 17(2) of the Charter.

Privacy and reputation: including protection from arbitrary interference with family life.²⁶⁷ This right is engaged when a child is removed from their family.²⁶⁸

Protection of families:²⁶⁹ The Charter recognises that families are the fundamental group unit of society and are entitled to be protected by society and the State.²⁷⁰ The right to family protection is not only a parental right, but also a right of the child.

Protection of children: “Every child has the right, without discrimination, to such protection as is in his or her best interests and is needed by him or her by reason of being a child.”²⁷¹

Although the Charter does not include the right to respite or other disability services, it does protect the right to protection of families and children without discrimination. Therefore, when a lack of access to support services compromises a family’s ability to provide effective ongoing care for a child with a disability, the right to family and the protection of the child’s best interests is at risk.

Further, the Charter requires public authorities to think about the best interests of the child and protection of families when making decisions about services. So, for example, although the primacy of the best interests of the child is not explicit in the *Disability Act 2006*, the Charter nevertheless obliges disability services to act in the best interests of the child.

If a child enters the child protection system or becomes a resident at a respite or other disability facility through relinquishment, additional Charter rights come into play. These include:

Right to life: which, in the context of child protection, may include a positive duty to protect the life of vulnerable children.²⁷²

Protection from cruel, inhuman and degrading treatment:²⁷³ which is concerned not only with physical integrity, but also with a person’s mental integrity and their inherent dignity as human beings.²⁷⁴ This right is of particular relevance in out-of-home care, including secure welfare and residential care settings.²⁷⁵

Cultural rights: including the child’s right to practise their religion, enjoy their culture and use his or her language. The distinct cultural rights of Aboriginal people are also protected.²⁷⁶

Fair hearing: including in child protection matters before the Children’s Court.²⁷⁷

Right to liberty and security:²⁷⁸ This right is engaged when an out-of-home placement of a child is sought, where a child is placed in a secure welfare facility or where a child is in the custody or under the guardianship of the Secretary of the DHS.

Right to humane treatment when deprived of liberty: for example, when a child is placed in secure welfare.²⁷⁹

267 *Charter of Human Rights and Responsibilities Act 2006* s 13.

268 In these circumstances, the interference must be lawful and reasonable in the particular circumstances, for example where the child is at risk of significant harm.

269 *Charter of Human Rights and Responsibilities Act 2006* s 17(1).

270 This contrasts with the *Children, Youth and Families Act 2005* s 10 (3)(a), where it is the “parent and child”, not “family”, that is described as the fundamental group unit of society.

271 *Charter of Human Rights and Responsibilities Act 2006* s 17(2). The best interest principle is also reflected in section 10(1) of the *Children, Youth and Families Act 2005*, which states that a child’s best interests must be the paramount consideration in decision making.

272 *Charter of Human Rights and Responsibilities Act 2006* s 9. For discussion of the positive duty see State of Victoria, Department of Human Services, *Protecting Victoria’s Children: Child Protection Practice Manual*, ‘Human Rights and Child Protection’, Advice No 1568 (31 December 2007).

273 *Charter of Human Rights and Responsibilities Act 2006* s 10.

274 Human Rights Committee, *General Comment 20: Concerning Prohibition of Torture and Cruel Treatment or Punishment (Art 7)*, 44th session, UN Doc HRI/GEN/1/Rev 6 (10 March 1992) [2].

275 State of Victoria, Department of Human Services, *Protecting Victoria’s Children: Child Protection Practice Manual*, ‘Human Rights and Child Protection’, Advice No 1568 (31 December 2007).

276 *Charter of Human Rights and Responsibilities Act 2006* s 19. Section 10(3)(c) of the *Children, Youth and Families Act 2005* also protects a child’s Aboriginal cultural and spiritual identity and development by, wherever possible, maintaining and building their connections to their Aboriginal family and community.

277 *Charter of Human Rights and Responsibilities Act 2006* s 24. See *Secretary, Department of Human Services v Catherine Sanding* [2011] VSC 42, unreported, 22 February 2011.

278 *Charter of Human Rights and Responsibilities Act 2006* s 21(1)–(3).

279 *Charter of Human Rights and Responsibilities Act 2006* s 22.

International obligations

Children with disability also have rights protected under international law. These are contained in the *Convention on the Rights of the Child* and the *Convention on the Rights of Persons with Disabilities*.²⁸⁰ Australia's ratification of these treaties creates a positive legal obligation to ensure adherence to these rights and principles within our laws, policies and practices.²⁸¹

Victoria's Charter is based on international human rights standards and contains a provision whereby international law may be considered when a statutory provision is interpreted.²⁸² Thus, the courts and government departments may consider rights contained in these conventions when interpreting the *Children, Youth and Families Act 2005* and the Disability Act.

The *Convention on the Rights of the Child* includes specific rights around removal from family, the right of young people to express views in matters affecting them, including a right to representation, responsibilities of families, and special protections when in child protection.²⁸³ A child's rights to family, health, an adequate standard of living and development, and education are also protected under this law.²⁸⁴

Similarly, the *Convention on the Rights of Persons with Disabilities* protects a child's rights to equality; accessibility; freedom from exploitation, violence and abuse; privacy, respect for home and family; and education and health.²⁸⁵ The Convention explicitly requires that, "In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration", to ensure they enjoy their rights and freedoms on an equal basis with other children.²⁸⁶

The United Nations Committee on the Rights of the Child has explicitly considered the rights of children with disability. It has stated that a child with disability living with a carer or parent should receive the support that would enable him or her to continue living with a parent if it is in his or her best interests. The Committee acknowledges the preventative benefits of providing support services before crisis point is reached and describes these as critical in maintaining a healthy, cohesive family unit. Relinquishment is such a crisis point.

Children with disabilities are best cared for and nurtured within their own family environment, provided the family is adequately cared for ... Support services should include different forms of respite care, such as care assistance in the home and day-care facilities directly accessible at community level. Such services enable parents to work, as well as relieve the stress and maintain healthy family environments.²⁸⁷

280 Rights also enjoyed under the *International Convention on Civil and Political Rights* and the *International Convention on Economic, Social and Cultural Rights*.

281 For example, the commitment of all Australian governments to the rights contained in *Convention on the Rights of the Child* is specified in the *Protecting Children is Everyone's Responsibility: National Framework for Protecting Australia's Children 2009–2020* endorsed by the Council of Australian Governments.

282 *Charter of Human Rights and Responsibilities Act 2006* s 32(2).

283 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577, arts 9, 12, 18, 20. (entered into force 2 September 1990).

284 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 3 UNTS 1577, arts 16, 24, 27, 29 (entered into force 2 September 1990).

285 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106, arts 5, 9, 16, 22, 23, 24, 25 (entered into force 3 May 2008).

286 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, A/RES/61/106, art 7 (entered into force 3 May 2008).

287 Committee on the Rights of the Child, *General Comment 9: The Rights of Children with Disabilities*, 27 February 2007, CRC/C/GC/9.

Human rights, best interests and relinquishment

“From a human rights perspective, all children have the right to experience the conditions for optimal health, growth and development, and society has an obligation to ensure that parents have the necessary resources to raise children.”²⁸⁸ This means children with disability have the right to the best possible life.

Implicit in this assertion is the question of what constitutes ‘best interests’. To answer it we must reframe a narrow view of best interests in child-safety terms to a more comprehensive approach that considers all the child’s human rights.

The best interests principle is grounded in international and domestic human rights law. It underpins both Victorian and federal policy around child protection and wellbeing, and is a legal obligation under the Charter.

The challenge remains, however, to strengthen the best interests principle in practice. It is necessary to ensure that putting the best interests of the child first is a priority across all aspects of government and community services’ engagement with children, not just those operating within the child protection system.

In policy and practice terms, this means shifting from a ‘child protection’ or ‘disability’ system to one that protects children. That is, meeting entitlements to services, including universal services such as education and health, consistent with a shared responsibility approach for children’s wellbeing, safety and protection.

It also requires access to specialist support services not only when they are needed but also for the duration of that need. On this model, all services are designed to improve outcomes for families with children with disability, thus minimising the risk of the child entering state care through relinquishment.

²⁸⁸ Reading et al (2008) cited in Brigid Jordan and Robyn Sketchley, *A stitch in time saves nine: Preventing and responding to the abuse and neglect of infants*, Australian Institute of Family Studies Child Abuse Prevention Issues No. 30 (2009).

The Victorian disability system

In Victoria, the *Disability Act 2006* provides a legislative framework for the provision of a range of services for people with disability.

The Act sets out the target group for disability services, provided either directly by the DHS or community service organisations who are registered providers of services.²⁸⁹

The Act provides principles for disability service provision, which state that disability services should, among other things:

- consider and respect the role of families and other people who are significant in the life of the person with disability
- acknowledge the important role families have in supporting people with disability, and in assisting their family member to realise their individual physical, social, emotional and intellectual capacities
- where possible, strengthen and build capacity of families who are supporting people with disability
- have regard for the needs of children with disability, and preserve and promote relationships between the child, their family and other people who are significant in the life of the child with disability.²⁹⁰

While the Act applies to people of all ages, it does have specific protections for children with disability. For example, section 5(3)(l) requires disability service providers to have special regard for the needs of children with disability and their families and caregivers.

The Act also requires that where a person is receiving regular disability services, their service provider must develop a support plan in consultation with them.²⁹¹ People with disability can also request assistance with planning.²⁹² The Act requires that planning should, where reasonably practicable, be individualised and tailored to the person's goals and needs, self-directed, and respectful of family, and should maximise choice, independence, inclusion and participation.²⁹³ Section 52(2) (d) requires the DHS Secretary (or her or his delegate) to, where possible, strengthen and build capacity within families to support children with disability when making a disability plan.

Disability services also have legal obligations under the Charter to act compatibly with human rights and take rights into account when making decisions, including when planning support.

The legislation obliges disability service providers to meet standards and for the DHS Secretary to monitor their performance.²⁹⁴ The Secretary has a range of powers to respond to breaches or to incompetent management of disability services.²⁹⁵ The Secretary, however, is also a service provider, which under current legislative arrangements provides the contradiction that the Secretary effectively regulates Secretary-provided (DHS) services, with no independent oversight of breaches of standards.

289 The Disability Act definition of disability is narrower than that in the Equal Opportunity Act. *Disability Act 2006* s 3, *Equal Opportunity Act 2010* s 4.

290 *Disability Act 2006* s 5(3)(h)–(l).

291 *Disability Act 2006* s 54.

292 *Disability Act 2006* s 53. If the person has an intellectual disability they are entitled to this assistance: See s 55.

293 *Disability Act 2006* s 52.

294 Under the Act, disability service providers must comply with the standards set out in *Quality Framework for Disability Services in Victoria (2007)*. These standards are determined by the Victorian Minister of Community Services.

295 *Disability Act 2006* s 99–103.

All disability service providers must have internal complaint processes, report on complaints and take steps to protect people who make complaints from victimisation.²⁹⁶ The Act also sets out a process of making complaints to the Disability Services Commissioner.²⁹⁷

Accessing disability services

Under the Act, the functions of the DHS Secretary include the obligation to develop and publish criteria to enable priority of access to disability services to be determined in a fair manner.²⁹⁸ This criteria is set out in the *Disability Services Access Policy*.²⁹⁹ This policy states that for a person to access disability services:

- they must have a disability (as defined by the Act)
- they must be considered a 'priority for access',³⁰⁰ and
- the disability service system must be the most appropriate system to meet that person's needs.³⁰¹

Specific program criteria sit underneath this broad policy.³⁰²

Parents may apply for an Individual Support Package (ISP) by registering on the Disability Support Register.³⁰³ In order to be eligible for a package, the child must have current, ongoing, unmet disability support needs that can be met through disability services.³⁰⁴

DHS allocates priority for an ISP where:

- children are living in facility-based care
- there is a risk of harm to the child or to others
- they are moving out of or avoiding moving into facility-based care

296 *Disability Act 2006* s 104–106.

297 *Disability Act 2006* s 107–128.

298 *Disability Act 2006* s 8 (2)(d).

299 State of Victoria, Department of Human Services, *Disability Services Access Policy*, July 2009.

300 Priority for access indicators include: the need to strengthen the supportive role of family, carers or support networks; safety risks (including to the child, their family, their carer or the community); multiple disadvantage; the impact if the service is not provided, availability of other supports and mandatory supports (for example, if the child is involved in the justice system). See *Ibid* 4, 21.

301 *Ibid* 8.

302 *Ibid* 5, 22.

303 State of Victoria, Department of Human Services, *Disability Support Register*, 2011 <<http://www.dhs.vic.gov.au/for-individuals/disability/start-here/disability-support-register>> at 25 January 2012.

304 *Ibid*.

- they have a rapid, degenerative condition
- they are in an extreme situation.³⁰⁵

If the application is successful, the child will be entered on the Disability Support Register. The family may then have to wait for funding and services to become available.

Range of services

There are a range of services available to support families and children with disability. These include facility-based respite; in-home support; behavioural programs including Behaviour Support Services (BSS, formerly known as Behavioural Intervention Support Teams) in each region; aids and equipment; funded specialist services for children with Autism Spectrum Disorders;³⁰⁶ the Family Options program; the Home and Community Care Program; and the Early Childhood Intervention Service.³⁰⁷

The priority of access to BSS services was recently developed by DHS under a Positive Practice Framework published in 2011. This includes “children and young people and other individuals whose family is at crisis point and imminent family breakdown is likely unless support is provided” as being within the criteria for determining urgency of access to services.³⁰⁸

305 Victorian Auditor-General's Office, above n 90, 10.

306 One of these is Mansfield Autism Statewide Services (MASS). MASS is an independent specialist school, and provides a range of services including consultancy, early intervention, family-camps and respite. MASS also has a travelling teacher service, which provides in-home support to families. See <<http://www.autismmansfield.org.au>> at 15 March 2012.

307 For children under the age of six, ECIS is administered by the Department of Education and Early Childhood Development.

308 State of Victoria, Department of Human Services, *Positive practice framework: A guide for behaviour support service practitioners*, 2011 <<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/positive-practice-framework-ppf>> at 27 February 2012.

The policy context

Support for children with disability and their families

In 2005, DHS published the *Review and Redevelopment of Support for Children with a Disability and their Families: Final Report*.³⁰⁹ Consistent with human rights, a major principle in the report is that families provide the best care for children with disability. The report acknowledged that this requires support for families, and so identified regular respite, family-centred support, early intervention, review and case planning for children in out-of-home care as other key principles.³¹⁰

The report also noted that if families are unable to continue day-to-day care of their child, the priority should be to provide alternative family care,³¹¹ shared care and other models that maintain family relationships.³¹²

This report indicated a clear policy intent that children with disability should be cared for by families, rather than by institutions.

Individualised funding

Victoria has been a national leader in shifting control and choice into the hands of people with disability. Over the past decade, disability policy has shifted from funding service providers to 'individualised funding'.

This shift was introduced under the *Victorian State Disability Plan 2002–2012*. The plan was intended to re-orient disability services towards individualised support – support that is flexible, tailored to the person's needs, self-directed and encourages community participation and informal support.³¹³

The move towards individual support was consolidated in 2008 when several programs for individualised funding were combined into one ISP.³¹⁴ Under the ISP model, rather than funding service providers, the person with disability receives funding to purchase support.³¹⁵

The Victorian Auditor-General's Office (VAGO) reported on individualised funding in September 2011. VAGO noted that individualised funding had real benefits, including giving greater flexibility and control to people with disability.³¹⁶ However, several criticisms were noted, along with significant unmet need for ISPs.³¹⁷

DHS accepted all of the Auditor-General's recommendations. As a result, Disability Services has developed a work plan to guide future developments and improvements, which includes a recently completed review of the Disability Support Register. DHS has informed the Commission that changes are now being put into place to simplify the application process and information and to ensure more consistent decision making.

National Disability Strategy

The National Disability Strategy is a 10-year plan to guide disability policy. It focuses on six priority areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and wellbeing. It was developed by the Australian, state, territory and local governments through the Council of Australian Governments (COAG), and endorsed on 13 February 2011.³¹⁸

309 Margaret Wagstaff, *Review and Redevelopment of Support for Children with a Disability and their Families: Final Report November 2004*, Department of Human Services, 2005.

310 Ibid 29–30.

311 Ibid 31.

312 Ibid 41.

313 The Victorian Government is currently preparing a new State Disability Plan, which must commence by 1 January 2013. *Disability Act 2006* s 37(1)(a).

314 Victorian Auditor-General's Office, above n 90, 2.

315 State of Victoria, Department of Human Services, *Individual Support Package Information Sheet*, August 2008.

316 Victorian Auditor-General's Office, above n 90, viii.

317 Ibid 12.

318 Department of Families, Housing, Community Services and Indigenous Affairs, *National Disability Strategy* (2010) <<http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx>> at 30 January 2012.

National Disability Insurance Scheme

As part of the National Disability Strategy, the Australian Government Productivity Commission conducted an inquiry into a long-term care and support scheme for people with disability in Australia. On 19 August 2011 COAG announced it would adopt the Productivity Commission's recommendations and implement a National Disability Insurance Scheme (NDIS).

The introduction of the NDIS represents a seismic shift in the way supports will be delivered to people with disability and, if properly resourced, provides an opportunity to shift from a welfare-based to a rights-based model of disability services.

The Productivity Commission set out a progressive implementation timetable, with a national rollout between 2015 and 2019.³¹⁹ COAG has committed to lay the foundations for the scheme by mid-2013.³²⁰

Autism State Plan

In May 2009 the previous Victorian Government released the *Autism State Plan*.³²¹ The plan aims to improve the quality of life for people with Autism Spectrum, their families and carers. However, it does not address the issue of unplanned out-of-home care – relinquishment.

The plan lists actions linked to priority areas: support, workforce expertise, linking services, education, and community participation, and developing an evidence base around autism spectrum disorder.³²² There continues to be significant work around early identification and response to autism based on the policy directions under this plan.

Policy initiatives to improve coordination between disability and child protection services

In 2008 DHS published the *Disability Services and Child Protection Protocol*. The protocol outlines principles for information sharing about shared clients, collaborative work around best interests planning, providing disability services to children and young people in child protection, and the involvement of disability services in the child protection process.³²³ This includes information for disability service workers on reporting wellbeing concerns, or abuse or neglect of children.³²⁴

More recently, DHS has built upon this work by developing the *Children, Youth and Families and Disability Services Operating Framework*. This sets out a number of actions to improve outcomes for children in out-of-home care and to strengthen working relationships between Children, Youth and Family Services (CYFS) and Disability Services. In practice, the framework is the work plan that makes the protocol operational and instigates improvements.

A governance group, which includes the Disability Services Commissioner and the Child Safety Commissioner, oversees a joint work plan for implementation. Actions have included:

- a review of planning for all children in voluntary out-of-home care funded by Disability Services
- an initial audit of children with a disability in out-of-home care
- implementing a system for ensuring consistency in the recruitment of foster carers and Family Options carers, and running additional training for Disability Services regional staff.

³¹⁹ Productivity Commission, above n 86, 934–6.

³²⁰ Jenny Macklin and Andrew Leigh, 'Progressing a National Disability Insurance Scheme' (Media Release, 6 December 2011).

³²¹ State of Victoria, *Autism State Plan*, May 2009.

³²² *Ibid* 22.

³²³ State of Victoria, Department of Human Services, *Protocol between Child Protection and Disability Services* 2008, 8.

³²⁴ *Ibid* 17–23.

The protocol and the integrated framework are important developments in improving collaboration and pathways between child protection and disability services. However, the recently completed Protecting Victoria's Vulnerable Children Inquiry noted concerns:

about service gaps in assessment and case planning for responses to the needs of children from homes where disability is present. Submissions [to the inquiry] argued that the protocol in place between statutory child protection and disability services was ineffective at supporting children with a disability.³²⁵

Consequently, that inquiry recommended that the protocol be strengthened, with more explicit statements around the roles and responsibilities of the different service agencies.³²⁶

Other structural reforms

DHS is currently structured across seven divisions and eight regions.³²⁷ Families of children with disability may receive services from multiple divisions, particularly CYFS and Disability Services. However, families often do not experience these services as a cohesive system.

In 2010, the department announced a 'One DHS' program of change, aimed at improving client outcomes and building a client-centred culture across the department.³²⁸ Within One DHS, the 'Future State' project looks at how clients experience DHS services.

Under the Future State arrangements, families will have one contact person within the DHS region and one care plan, rather than having to deal with multiple people, processes and organisations. This is being trialled in Southern Metropolitan and Barwon South West regions from January 2012.

It should also be noted that one set of DHS standards will apply to registered disability services, family service and out-of-home care providers and will commence on 1 July 2012.³²⁹

325 State of Victoria, Department of Premier and Cabinet, above n 132, Vol 2, 224–225.

326 Recommendation 21, State of Victoria, Department of Premier and Cabinet, Ibid Vol 1, lii.

327 The organisational structure of DHS is currently under review.

328 Department of Human Services, *Department of Human Services Annual Report 2010–2011*, September 2011, 12.

329 State of Victoria, Department of Human Services, *Transition to the Department of Human Services Standards: Information for funded organisations* (November 2011) <http://www.dhs.vic.gov.au/__data/assets/word_doc/0011/674939/business_relation_transition_factsheet_1111.doc> at 8 March 2012.

The Victorian child protection system

The predominate legislation relating to child protection in Victoria is the *Children, Youth and Families Act 2005*. It regulates community services that provide support to vulnerable families and children. The Act provides the legislative basis for the statutory child protection system – from reporting, investigation and protective interventions by the Department of Human Services (DHS) to consideration of protection applications by the Children’s Court and placement of children in out-of-home care.³³⁰

It also regulates community services that provide support to vulnerable families and children.³³¹

The Act contains decision-making principles for community services, DHS child protection and the court, centred on the “best interests of the child”.³³²

The Children, Youth and Families Act and the Victorian Charter of Human Rights and Responsibilities (the Charter) require that the best interests of the child must be the foremost consideration when child protection, family services or the Children’s Court takes an action or makes a decision about a child.³³³ Best interests includes the need to protect children from harm, to protect children’s rights and promote children’s development.³³⁴

The ‘best interests of the child’ principle is intended to be “the foundation of the Act and the basis for all decision making and actions”.³³⁵ Consistent with this, DHS have produced a range of resources, including the Best Interests Framework, Best Interest Case Practice Model and Best Interest Plans³³⁶ to support the day-to-day work of child protection practitioners across Victoria.³³⁷

Decision-making principles contained in the Act highlight the importance of consultation and collaboration with families, and fair and transparent decision making.³³⁸

There are additional decision-making principles that apply to decisions about Aboriginal children. These acknowledge the importance of consulting with the Aboriginal community and the child’s extended family.³³⁹ The Act also contains an Aboriginal Child Placement Principle, which states that as a priority, wherever possible the child must be placed within the Aboriginal extended family or relatives and where this is not possible other extended family or relatives. Placements must allow the child to maintain contact with family, culture and community.³⁴⁰

335 Victorian Government, *The Children, Youth and Families Act 2005 and the Child Wellbeing and Safety Act 2005: A framework to promote children’s safety, wellbeing and development*, April 2006, 2.

336 KPMG, ‘Evaluation of the Child and Family Services Reforms’ *Interim Report 1 to Department of Human Services* (September 2009) 40.

337 The Commission welcomes the fact that the DHS *Child Protection Practice Manual* highlights the obligation to consider human rights when making decisions and provides guidance on balancing competing rights and determining the best interests of the child. State of Victoria, Department of Human Services, *Protecting Victoria’s Children: Child Protection Practice Manual, ‘Human Rights and Child Protection’, Advice No 1568 (31 December 2007)*.

338 *Children, Youth and Families Act 2005* (Vic) s 11.

339 *Children, Youth and Families Act 2005* s 12.

340 *Children, Youth and Families Act 2005* s 13.

330 *Children, Youth and Families Act 2005*, chapter 4.

331 *Children, Youth and Families Act 2005*, chapter 3.

332 *Children, Youth and Families Act 2005*, part 1.2.

333 *Children, Youth and Families Act 2005* s 10.

334 *Children, Youth and Families Act 2005* s 10(2). Section 10(3) also sets out in more detail the factors to consider in determining the best interests of the child. These include the need to protect the relationship of the parent and child, to limit interference to that necessary to secure the safety and wellbeing of the child, and the need to promote positive relationships between the child, parents, family and other significant people.

The Act is also the legislative platform for Child FIRST (Child and Family Information Referral and Support teams) designed to provide specialised support for vulnerable Victorian children and their families and prevent unnecessary involvement with Child Protection.

The *Child Wellbeing and Safety Act 2005* was companion legislation to the Children, Youth and Families Act and sets out general principles that guide all services for children.³⁴¹ This is not limited to child protection services and applies to any services for children. The principles reflect a focus on early intervention, support for families and a broad concept of children's welfare.

These two laws were elements of the previous Victorian Government's Every Child Every Chance strategy. In connection with this strategy, the government pursued a number of specific reforms within the child and family services sector.³⁴² These included the introduction of Child FIRST (Child and Family Information, Referral and Support Teams) and Integrated Family Services, implementation of the best interests principles in decision making, information sharing and reforming ways of working with Aboriginal children and families,³⁴³ and service standards for community service organisations delivering out-of-home care and family services.³⁴⁴

341 *Children, Youth and Families Act 2005* s 5.

342 These are reviewed in KPMG, above n 336, 2–5.

343 The Commission notes and supports the notion of the protective value of culture, as included in the DHS *Aboriginal Cultural Competence Framework*. We also acknowledge the policy commitments made through *Dardee Boorai: Victorian Charter of Safety and Wellbeing for Aboriginal Children and Young People* and the development of the *Victorian Government Aboriginal Inclusion Framework 2010* to support the engagement of Indigenous Australians with government agencies, including universal services.

344 DHS is currently consolidating various service standards for family and out-of-home care, disability and homelessness services into one set of Human Services Standards. These will commence in July 2012.

Since the change of government in December 2010, the term 'every child, every chance' has been used less frequently. However, key themes – a focus on the best interests of the child, a public health model with a focus on early intervention and structural reform – are continuing, along with a stronger emphasis on shared responsibility for the wellbeing of vulnerable children across government. Significantly, a far-reaching Inquiry into Protecting Victoria's Vulnerable Children has just been completed. These are discussed in more detail at the end of this chapter.

Navigating the child protection system

Most families' first interaction with the Child Protection Service is because someone has reported a significant concern about the wellbeing of a child, or a belief that a child is in need of protection. A wellbeing report can be made to the Secretary of DHS or to Child FIRST.³⁴⁵

Child FIRST is intended to be a secondary service – providing specialised support for families and children at risk. Commonly, Child FIRST will develop a plan with the family to "support the child's healthy development and improve parenting capacity".³⁴⁶ The plan can include linking the family to support services, with the aim of preventing harm to the child and matters escalating to include child protection services.³⁴⁷

345 *Children, Youth and Families Act 2005* s 28, 31.

346 Victorian Government, Department of Human Services, *Child FIRST Factsheet*, November 2008, <<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/child-first-fact-sheet>> at 15 January 2012.

347 *Ibid.*

If the Secretary receives a wellbeing report, the Secretary may:

- provide advice to the person who made the report
- provide advice and assistance to the child and family that are the subject of the report
- refer to the child and family to Child FIRST or another support service
- determine that there are concerns that warrant further investigation and intervention by child protection.³⁴⁸

Entering out-of-home care

In some cases, when the Child Protection Service assesses that the level of risk is too great for the child to remain in the care of their parents, they will seek to place the child in out-of-home care. A child may enter out-of-home care through a Child Care Agreement, otherwise known as a 'voluntary agreement', or an order by the Children's Court.³⁴⁹

Voluntary placements

A voluntary placement occurs when a parent or guardian enters into an agreement with a service to provide care for a child. The service may be the DHS, a registered out-of-home care provider or a disability service.

Child Care Agreements are made under section 3.5 of the Children, Youth and Families Act and can be made with or without child protection involvement.

The Children's Court

More commonly, a child enters out-of-home care subject to a protection order issued by the Children's Court.³⁵⁰ The court is able to make a variety of orders, ranging from temporary orders or orders where the child remains with their parent/s, to orders that affect the custody and guardianship of the child.³⁵¹ The court cannot make an order removing a child from the custody of his or her parent, unless:

- the court considers, and rejects as not in the child's best interests, an order that retains parental custody, and
- the court is satisfied that the Secretary has taken all reasonable steps to provide the services necessary to enable the child to remain in the custody of his or her parent.³⁵²

The out-of-home care system

There are several forms of out-of-home care. Broadly, these can be divided into home-based care (care in a non-parent's home) and residential care (care by professional staff in a residential facility).³⁵³

348 State of Victoria, Department of Human Services, 'Substantiation and determination of level of risk', *Child Protection Practice Manual* 23 April 2007, Advice no:1213. <<http://www.dhs.vic.gov.au/cpmanual/out-of-home-care>> at 26 March 2012.

349 Several key informants expressed concerns about these agreements in the child protection context, arguing that rather than being voluntary, families feel forced to sign these agreements as the DHS will seek a court order if the family refuses to sign.

350 At 30 June 2011, 81 per cent of Victorian children in out-of-home care were subject to a care and protection order. See: Australian Institute of Health and Welfare, *Child protection Australia 2010–11*, 2012, Child welfare series no. 53, Cat. no. CWS 41, 34–35.

351 Family Division, Children's Court of Victoria, *Court Orders*, 2011, see <<http://www.childrenscourt.vic.gov.au/CA256CA800017845/page/Family+Division-Court+Orders?OpenDocument&1=20-Family+Division~&2=40-Court+Orders~&3=~>> at 15 January 2012.

352 *Children, Youth and Families Act 2005* s 276 (2).

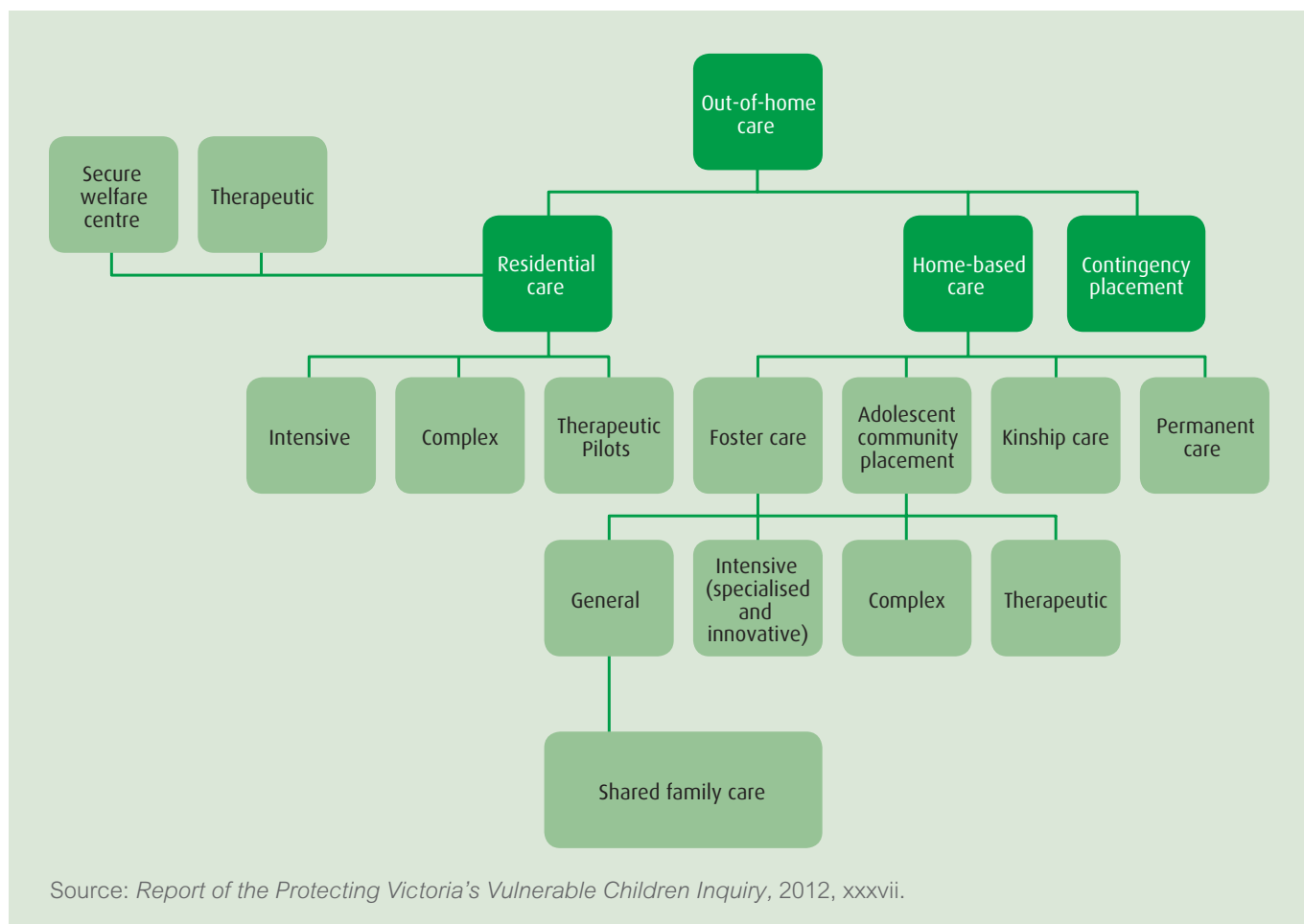
353 Centre for Excellence in Child and Family Welfare, *Issues paper 2: Their needs: Appropriate service models for vulnerable children, young people and families, Protecting Victoria's Vulnerable Children Inquiry* 2011, 2011, 4.

Home-based care includes:

- kinship care – the child is cared for by an approved relative or close friend (the preferred form of out-of-home care in Victoria)³⁵⁴
- foster care – the child is cared for by accredited volunteers in their own homes
- therapeutic foster care or the ‘Circle Program’ – specially trained foster carers provide a therapeutic care environment in partnership with a therapeutic service
- adolescent community placements – accommodation and support for those aged 12 to 18 with trained voluntary carers in the local area.³⁵⁵

Residential care is for children and young people who are unable to be placed in home-based care, and varies based on the behaviours and needs of the child or young person. It also includes ‘lead tenant’ accommodation for young people who are transitioning from state care to independent living.³⁵⁶

Figure 2: Victoria’s out-of-home care system



354 State of Victoria, Department of Human Services, ‘Flowchart of placement in out-of-home care’, *Child Protection Practice Manual*, Advice No 1397, 23 April 2007, 4. <<http://www.dhs.vic.gov.au/cpmanual/out-of-home-care>> at 26 March 2012.

355 <<http://www.dhs.vic.gov.au/for-individuals/children,-families-and-young-people/kinship-foster-and-other-care/foster-care-information>> at 23 January 2012.

356 <<http://www.dhs.vic.gov.au/for-individuals/children,-families-and-young-people/kinship-foster-and-other-care/residential-care>> at 23 January 2012.

Key policy directions in child protection

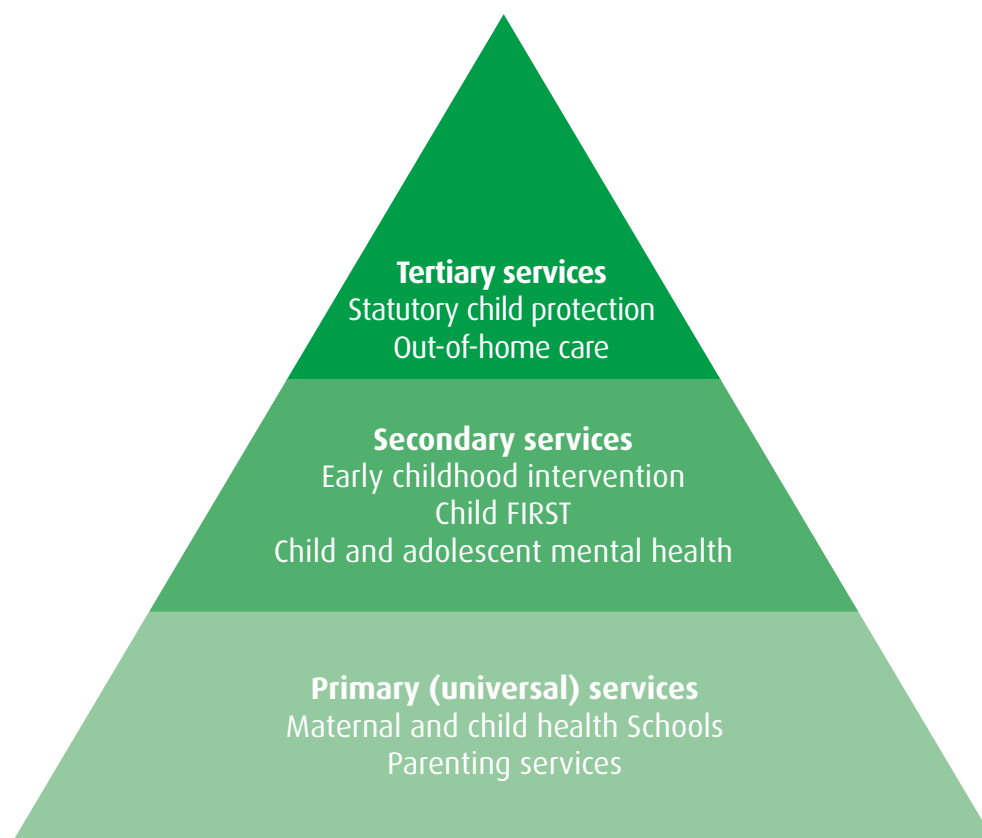
The Victorian child protection system has undergone significant reform over the last decade, signalling a shift towards a public health model of child protection. Accordingly, legislation and policy reflects an increasing emphasis on early intervention and flexibility in child protection responses. Reforms have also focused on decision making, particularly the central concept of the best interests of the child. Most recently, the government has focused on reforming the structure and workforce of DHS.

The public health model as the basis of reform

The public health model of child protection classifies services into three levels: universal (primary), secondary and tertiary. Universal services are provided to all children and families and are aimed at building community resources and addressing social factors that lead to neglect or abuse.³⁵⁷ Secondary services are targeted at children who are at risk of maltreatment and tertiary services are aimed at children who have already experienced neglect or abuse.³⁵⁸

The public health model is intended to shift the child protection system from merely responding to abuse and neglect to promoting the safety and wellbeing of children. For example, the Children, Youth and Families Act creates specific roles for community-based child and family services – to receive child-wellbeing concerns, to assess needs and provide support to families, and to be an entry point for families into an integrated network of services.³⁵⁹ Child FIRST was established at a sub-regional level throughout Victoria to fulfil this function.³⁶⁰

Figure 3: Victorian services within a public health model ³⁶¹



³⁵⁷ Cathryn Hunter, *Defining the public health model for the child welfare services context* (2011) Australian Institute of Family Studies.

³⁵⁸ The Allen Consulting Group, *Inverting the Pyramid: Enhancing Systems for Protecting Children*, 2008, ix.

³⁵⁹ *Children, Youth and Families Act 2005* s 22.

³⁶⁰ State of Victoria, Department of Human Services, above n 346.

³⁶¹ Adapted from Bromfield & Holzer (2008), cited in Jordan and Sketchley, above n 288.

This prevention focus is consistent with the Charter as the bulk of the effort is on supporting the family and child to enjoy their human rights. Properly resourced, planned and accessible interventions will also help prevent children with disability from entering the tertiary end of the system, allowing them to enjoy their right to protection of the family without interference.³⁶²

The public health model has been adopted at a national level, through the *National Framework for Protecting Australia's Children* (National Framework).³⁶³ The National Framework identifies six supporting outcomes relating to safe and supportive families, risk factors, and support for children who have experienced abuse and neglect. Each of these outcomes is linked to strategies, at both state and federal levels, and indicators of change.³⁶⁴ The National Framework also identifies specific projects, such as developing *National Standards for Out of Home Care*.³⁶⁵

Shared responsibility

A strong thread underpinning the public health model is that the whole of society shares responsibility for the wellbeing of children. This is explicitly stated in the Child Wellbeing and Safety Act and in the National Framework.³⁶⁶ In addition, under the Charter, all public authorities have responsibility to uphold human rights, including protecting the best interests of children.³⁶⁷ This means that the rights and welfare of children with disability is a shared responsibility across the whole of government, including in disability, health and education services.

362 The Commission notes and welcomes the new Placement Prevention Pilots introduced under Directions for Out-of-home Care. This program facilitates Placement Prevention Coordinators to refer a family that are at risk of having their child(ren) removed to a caseworker who undertakes a needs assessment to ensure the right suite of therapeutic services and support are in place to assist the family over a period of up to one year. The Commission understands that this program will be evaluated in 2012.

363 Council of Australian Governments (COAG), *Protecting Children is Everyone's Business: National Framework for Protecting Australia's Children 2009–2020*, 2009, 7.

364 Ibid 11–12.

365 National Standards for out-of-home-care came into effect in July 2011. <http://www.fahcsia.gov.au/sa/families/pubs/nat_std_4_outofhome/Pages/default.aspx> at 15 January 2012.

366 *Child Wellbeing and Safety Act 2005* s 5(1)(a); Council of Australian Governments, above n 363.

367 *Charter of Human Rights and Responsibilities Act 2006* s 17(2).

Workforce

Workforce problems in child protection have been a long-standing issue. High staff turnover has led to considerable vacancy rates and substantial numbers of inexperienced staff.³⁶⁸ These problems compromise the continuity of relationships between families and workers. In response, the government announced a child protection workforce strategy in 2011.³⁶⁹ Changes will include an increase in the percentage of staff who work directly with children, new roles in each region for principal practitioners and practice leaders, and new arrangements to link child protection with Child FIRST.³⁷⁰

System capacity

Despite the leadership shown in instigating these reforms and the efforts of front-line workers in child protection and out-of-home care, successive investigations indicate that the system has failed to protect the best interests of children. For example, in recent years the Victorian Ombudsman conducted two own-motion investigations into the child protection system and out-of-home care, which revealed systemic failures and significant breaches of children's rights.³⁷¹

There are significant gaps in preventative services in Victoria. Many families miss out on secondary services, such as family support, and the system remains heavily weighted towards tertiary services.³⁷² In its evaluation of child protection reforms, KPMG identified that demand pressures in some Child FIRST catchments were limiting capacity for early intervention.³⁷³

Thus, while the Commission welcomes the investment made so far in prevention and early intervention, these observations raise doubt that Victoria can deliver on a public health model of child protection in the absence of significant additional resources.

368 Ombudsman Victoria, above n 136, 108–109.

369 State of Victoria, Department of Human Services, *Protecting Children, changing lives: Supporting the child protection workforce*, July 2011.

370 Ibid 12.

371 Ombudsman Victoria, above n 61; Ombudsman Victoria, n 136. The Commission notes and supports the recommendations made by the Ombudsman in his own-motion investigations into the child protection and out-of-home care systems. The Commission also welcomes the acceptance of all but one of these recommendations by DHS.

372 For example, the Ombudsman found that overflow from child protection was positioning Child FIRST not as a secondary service, but as a "de facto child protection program". Ombudsman Victoria, above n 136, 42.

373 KPMG, above n 336, 3.

The Protecting Victoria's Vulnerable Children Inquiry

In January 2011, the government opened the Protecting Victoria's Vulnerable Children Inquiry (the Inquiry) with broad terms of reference to investigate systemic failures in the child protection system and measures to prevent neglect and abuse.³⁷⁴ The Inquiry report was tabled in Parliament on 28 February 2012.

Previous reviews have tended to focus on discrete aspects of the child protection system. In contrast, this Inquiry considered:

... government's overall response to child abuse and neglect. This scope has included family support services in addition to statutory child protection services, but has also considered the effectiveness of the roles and responsibilities of the government and the community sector in working together to meet the needs of vulnerable children.³⁷⁵

The Inquiry made 90 recommendations to strengthen and improve the protection and support of vulnerable young Victorians, identifying a further 20 findings and matters for attention.

These recommendations contribute to 10 major system reforms identified as necessary by the Inquiry, set out in Table 6.

Table 6: Major system reforms for protecting children through a system that prevents and responds to child abuse and neglect³⁷⁶

1	The development and implementation of a Vulnerable Children and Families Strategy – a whole-of-government vulnerability policy framework with the objective of focusing on a child's needs (overseen by government through a Cabinet sub-committee)
2	A sector-wide approach to professional education with greater development and application of knowledge to inform policy and service delivery
3	Clearer departmental and agency accountability for addressing the needs of vulnerable children, in particular, health and education
4	Expanded Vulnerable Child and Family Service Networks
5	An area-based approach to co-located intake with clear accountability for decision making on statutory intervention
6	Strengthening the law and its institutions
7	Out-of-home care funding and services aligned to a child's needs
8	Improved community sector capacity with a clearer governance and regulatory framework
9	A strengthened regulatory and oversight framework
10	A plan for practical self-determination for guardianship and Aboriginal children in out-of-home care and culturally competent service delivery
11	A sector-wide approach to professional education with greater development and application of knowledge to inform policy and service delivery

³⁷⁴ See <<http://www.childprotectioninquiry.vic.gov.au>> at 17 January 2012.

³⁷⁵ State of Victoria, Department of Premier and Cabinet, above n 132, Vol 1, xxix.

³⁷⁶ Ibid Vol 1, xl.

Consideration of relinquishment by the Inquiry

The Inquiry did not consider the issue of relinquishment directly. However, it did note that for some children with disability, “the only protective concern is the child’s parents’ inability to provide the level of care required for that child or young person,” noting previous findings by the Victorian Law Reform Commission that protection applications are sometimes made so as to secure services for such children.³⁷⁷

The inquiry saw this as “indicative of a serious gap in service delivery”. In its view, “prioritising service delivery should not be the function of protection applications. If children are missing out on services provided under other Acts (for example, under the *Disability Act 2006*) this should be addressed in prioritising services to children and young people under those Acts”.³⁷⁸

Although relinquishment was not a focus for the Inquiry, its analysis of how vulnerable children and families fare in our universal, secondary and tertiary systems is instructive in identifying ways to prevent relinquishment, and to respond better when it does occur.

Among the 90 recommendations made by the Inquiry, those of particular relevance to this research promote shared responsibility for protecting the rights and wellbeing of vulnerable children, which may include children with disability.

In particular, the recommendation to develop and adopt a whole-of-government Vulnerable Children and Families Strategy provides an opportunity to ground efforts to prevent relinquishment inside a focused effort to improve outcomes for vulnerable children.³⁷⁹

Similarly, recommendations made to the Department of Education and Early Childhood Development (DEECD) and the Department of Health – to hold universal services accountable for the support they provide to vulnerable children and families – go directly to the issues raised in this research.³⁸⁰

The Inquiry recommendations also have a strong focus on pathways, case planning processes and collaboration within DHS. The Inquiry specifically recommends that the protocol between statutory child protection and disability services be strengthened. The panel also recommended that the Disability Act, and other relevant legislation, be amended to make clear the responsibilities of services to act in the best interests of children and young people, and to prioritise service delivery to vulnerable children, young people and their families.³⁸¹

Given the over-representation of children with disability in out-of-home care, the recommendation to establish an independent Commission for Children and Young People with additional oversight powers is significant, as is the recommendation to establish a comprehensive five-year plan for out-of-home care.³⁸²

377 Ibid Vol 2, 339.

378 Ibid.

379 Recommendation 2, Ibid Vol 1, i. See also recommendations 3, 4, 80, 82, 83.

380 Recommendations 11, 13, 14, 15, 17, 81, Ibid Vol 1, li–lii, lxii.

381 Recommendations 18, 21, Ibid Vol 1, lii.

382 Recommendations 25, 89, Ibid Vol 1 liii, lxiv.

Glossary

Aids and Equipment Program

This Victorian Aids and Equipment program offers funding towards the cost of functional aids, equipment and home modifications for people with disability. In addition to this program, the Department of Human Services funds assistive technology programs, such as equipment information services, equipment libraries and specialist equipment design.

Affirming Families Program

Affirming Families is a behaviour intervention program specifically for families of children (2 to 16) with disability or developmental delay and behavioural issues in Melbourne's north or west.

Applied Behaviour Analysis (ABA)

A method of addressing behaviour, based on structured one-on-one teaching and positive reinforcement. ABA is used by many families of children with autism, but it is not a funded program.

Asperger's syndrome

People with Asperger's syndrome experience difficulty understanding and expressing emotions, have restricted interests and show repetitive behaviours. People with Asperger's syndrome usually have intelligence within the normal range.

Attention deficit hyperactivity disorder (ADHD)

A condition characterised by inability to regulate and maintain behaviour, often involving overactivity and poor concentration. This can affect social relationships and academic work.

Autism

A condition involving abnormal or impaired development, including difficulties with social skills, lack of imaginative thought, communication impairment and obsessive or repetitive behaviours.

Autism spectrum disorder (ASD)

A group of developmental disorders with a similar pattern of behaviour in three key areas – communication, social interaction and imaginative thought. Includes autism, Asperger's syndrome and Pervasive Developmental Delay – Not Otherwise Specified (PDD-NOS). ASD may also coexist with other disabilities, including intellectual disability, speech and language disorders.

Best interests principle

Under the *Children, Youth and Families Act 2005*, the best interests of a child must be the first consideration in any action taken or decision made in relation to a child. Best interests includes the need to protect children from harm, protect their rights and promote their development. Victoria's Charter of Human Rights and Responsibilities (the Charter) and international human rights law also include the right of children to protection in their best interests.

Behaviours of concern

Behaviour that poses a risk to an individual, to other people or to property. Sometimes, this behaviour is in response to experiences or environments that have a negative effect on the person. Also called 'challenging behaviours'.

Behavioural Support Services (previously Behaviour Intervention Support Teams)

A DHS service for people with very complex and challenging behaviours. Services range from education and training to long-term direct intervention.

Case management

Disability services case managers work directly with people with disability and their families. They assist people to identify, organise and plan supports to meet individual needs. If and when Child Protection becomes involved with a child they take on the primary case management responsibility for the child. In some circumstances, Child Protection may contract case management responsibility to a registered community service organisation.

Centralised Respite System Business Rules

A set of rules for how respite services operate. These rules include topics such as operating hours, fees, placements, cancellations, decision making and communication pathways.

Cerebral palsy

The term cerebral palsy describes a range of conditions that affect muscle control, movement and posture. Cerebral palsy is caused by damage to the developing brain.

Child and Adolescent Mental Health Service (CAMHS)

A service to provide assessment and treatment for children and adolescents up to 18 years who are experiencing significant psychological distress and/or mental illness.

Child Care Agreement

An agreement to place a child voluntarily in a placement outside the home made between parents and an out-of-home care or disability provider. Child care agreements are regulated by the *Children, Youth and Families Act 2005*.

Child FIRST (Child and Family Information Referral and Support Teams)

A community-based referral service to connect vulnerable children, young people and families to local services.

Child Protection Service

The Child Protection Service (Child Protection) operates within the Children, Youth and Families Division of the Department of Human Services. Its functions are to investigate matters where it is alleged that a child is at risk of harm; refer children and families to services that assist in providing the ongoing safety and wellbeing of children; take matters before the Children's Court if the child's safety cannot be ensured within the family; supervise children on legal orders granted by the Children's Court; and provide and fund accommodation services, specialist support services, and adoption and permanent care to children and adolescents in need.

Child Safety Commissioner

The Child Safety Commissioner has a range of functions in relation to child safety. These include promoting child-safe environments, monitoring out-of-home care and conducting inquiries into child deaths where children were known to the Child Protection Service.

Client Relationship Information System (CRIS) and Client Relationship Information System for Service Providers (CRISSP)

CRIS is a database of Department of Human Services client information and case management. CRISSP is a free web-based database that the department offers to funded community service organisations.

Contingency Placement

Placements of children within the child protection system that are outside funded placements, made on an ad hoc or emergency basis.

Council of Australian Governments (COAG)

A forum for work and negotiation across different levels of government. It consists of the Prime Minister, State Premiers, Territory Chief Ministers and the President of the Australian Local Government Association.

DEECD

Department of Education and Early Childhood Development.

DHS

Department of Human Services.

Disability Services Commissioner

The Disability Services Commissioner works with people with disability, and disability service providers, to resolve complaints. The Commissioner also has education, training and research functions.

Disability Support Register (DSR)

A DHS register of people with confirmed need for ongoing disability support, including Individual Support Packages (ISP). The DSR is used to allocate supports when funding and vacancies become available.

Discrimination

Discrimination is treating, or proposing to treat, someone unfavourably because of a personal characteristic protected by law. In Victoria, this includes a range of characteristics, including age and disability. Discrimination also includes imposing unreasonable requirements, conditions and practices that disadvantage, or could disadvantage, people with a particular personal characteristic.

Down syndrome

A genetic condition resulting from an extra chromosome. Down syndrome involves a range of physical characteristics, effects on health and development, and some level of intellectual disability.

Early Childhood Intervention Service (ECIS)

A service for children under the age of six with disability or developmental delay, administered by DEECD. ECIS includes flexible support packages for children with high support needs, parental support and education programs.

Facility-based respite

Overnight, extended or emergency support for people with high support needs, in a facility away from the person's home.

Family Coaching Victoria

A 12-month pilot program of intensive casework and coordinated service provision with families referred by Child Protection as being at immediate risk of coming into out-of-home care for the first time or whose children have just come into care for the first time. The purpose of the program is to prevent placement in out-of-home care and achieve a rapid family reunification.

Family Options

The Family Options program supports families to share care of a child with disability with a volunteer carer, on a short- or long-term basis. Funded by DHS and delivered by community service organisations, Family Options placements are gradually being transferred into Individual Support Packages.

Foster care

Care for children in the home of an accredited foster carer who is not a family member. Part of Victoria's child protection and out-of-home care system.

Helping Children with Autism Package

An Australian Government package that funds early intervention for young children with Autism Spectrum Disorders (ASD), Autism Advisers, and a range of support services and Medicare items.

Home and Community Care (HACC) Programs

HACC programs include a range of services, such as domestic assistance, nursing, allied health services and respite. Local councils are major providers of HACC services.

Home-based care

Home-based out-of-home care includes kinship care, foster care and permanent care.

(DHS) Incident Reporting System

A system for reporting incidents involving DHS staff or clients. Incidents that must be reported range in severity from incidents where there is a risk of death, injury or sexual or physical assault, to neighbourhood complaints.

Individual Support Package (ISP)

An ISP is a package of funds allocated by DHS to a person to meet their disability support needs.

In-home support or respite

Services aimed at providing respite through disability support within the person's home.

Interim Placement Program (IPP)

A family-based program designed to give families a short-term break while they deal with a stress factor. This program operates in the Southern Metropolitan Region.

Kinship care

Care of a child by a family member (other than a parent) or a friend.

Mansfield Autism Statewide Services (MASS): Mansfield Autism School and Travelling Teacher Program

A DHS-funded independent specialist school that provides a range of services including consultancy, early intervention, family-camps and respite. MASS runs a travelling teacher service, which provides in-home support to families.

National Disability Advocacy Program

An Australian Government program that funds different types of advocacy – citizen advocacy (matching people with disability with volunteers), individual advocacy, legal advocacy, self-advocacy (supporting people with disability to advocate on their own behalf), family advocacy (supporting family members to act as advocates) and systemic advocacy.

Obsessive-compulsive disorder

A severe anxiety disorder involving persistent intrusive thoughts or images (obsessions) and repetitive behaviour that is excessive and distressing (compulsions).

Out-of-home care

Care for children under 18 years of age who are unable to live with their parents. Out-of-home care includes home-based and residential care.

Oppositional defiant disorder (ODD)

ODD is characterised by a pattern of hostile and or negative behaviour, particularly towards authority figures. To be classified as ODD these behaviours must be more severe than those of their peers, and must persist for more than six months.

Permanent care

Children come to permanent care through the Child Protection Service. A permanent care order by the Children's Court gives custody and guardianship of a child to a person who is neither the child's parents nor the Secretary of DHS.

Protecting Victoria's Vulnerable Children Inquiry

The state government announced the Protecting Victoria's Vulnerable Children Inquiry on 31 January 2011. The Inquiry was tasked with investigating systemic problems in Victoria's child protection system and making recommendations to strengthen and improve the protection and support of vulnerable young Victorians. The Inquiry Panel, comprised of the Honourable Philip Cummins, Professor Emeritus Dorothy Scott OAM and Mr Bill Scales AO presented its Report to the Minister for Community Services on 27 January 2012.

Protective concerns

A concern that a child is ‘in need of protection’. Under the *Children, Youth and Families Act 2005* a child is in need of protection if:

- they are abandoned, or their parents are dead or incapacitated, and there is no other suitable person willing or able to care for the child, or
- they have suffered, or are likely to suffer, significant harm due to physical, sexual, emotional or psychological abuse and the child’s parents have not protected, or are unlikely to protect, the child from harm of that type, or
- their health or physical development has been, or is likely to be significantly harmed due to the non-provision of medical care.

Public Health Model

A model of children’s welfare protection that classifies services into three levels: universal, secondary and tertiary. Universal services, such as health and education, are provided to all children and families. Secondary services target children at risk of abuse or neglect (for example, early intervention). Tertiary services respond to children who have already experienced abuse or neglect (for example, the Child Protection Service).

Reactive attachment disorder

Disorder characterised by a severely disturbed ability to relate to others. May be caused by severe parental abuse or neglect, or lack of stable attachments due to repeated changes in care.

Residential care

Part of Victoria’s child protection and out-of-home care system, this is care for children and young people by professional staff in community-based residential facilities.

Residential service

Part of the disability service system and sometimes called supported accommodation. Accommodation in group homes or Community Residential Units for adults with disability, supported by rostered staff members. The term Community Residential Unit will shortly be removed from the *Disability Act 2006*, as the definition of residential service is being clarified under that legislation.³⁸³

³⁸³ Disability Amendment Bill 2012.

Respite

Respite is often described as an outcome, rather than a service. In this sense, respite is an opportunity for carers and families to rest and recharge so that they can continue in their caring role. Respite can be provided through many forms of services, including facility-based respite, in-home support, community-based respite, and day and recreation programs.

Secure Welfare Services

Secure Welfare Services (SWS) are for children aged 10 to 17 who present substantial and immediate risks to themselves or others, where the broader child protection system cannot manage that risk. SWS involves containment and is the most restrictive form of child protection intervention in out-of-home care.

Separation anxiety disorder

A childhood disorder, where children experience excessive anxiety about being separated from home, their parents or other significant people.

Shared care

Arrangements where a child is cared for at home for several days a week, and in a residential or family-based placement for the remainder of the week.

Transitional housing

Transitional housing usually means fixed-term accommodation that facilitates transition to another form of housing and forms part of the homelessness system. However, in the context of relinquishment, ‘transitional housing’ is used to refer to community-based facilities with professional staff where children with disability reside on a long-term basis.

Tourette syndrome

A neurological disorder characterised by repetitive movements (tics) or involuntary vocalisations.

Victorian Aboriginal Disability Network

A network of Aboriginal people with disability in Victoria that works towards understanding community needs, teaching about rights and improving access to services.

Appendix 1: List of key informant interviews

Children's Court of Victoria	23 September 2011
Disability Discrimination Legal Service	5 October 2011
Villamanta Disability Rights Legal Service	17 October 2011
MacKillop Family Services	24 October 2011
Office of the Child Safety Commissioner	27 October 2011
Youth Disability Advocacy Service	27 October 2011
Southwest Advocacy Association and Community Connections Warrnambool	8 November 2011
Association for Children with Disability	9 November 2011
VISTA – EW Tipping Foundation	9 November 2011
Disability Services Commission	11 November 2011
Yooralla (Benalla)	15 November 2011
Autism Victoria (Amaze)	16 November 2011
Victoria Legal Aid	22 November 2011
St Luke's Children, Youth and Family Services	7 December 2011
CREATE Foundation	13 December 2011
Department of Human Services	15 and 19 December 2011
Yooralla	16 December 2011
Victorian Aboriginal Disability Network	16 January 2011
Berry Street	18 January 2012

Appendix 2: Local Government Areas in which no facility-based respite centres are located

Alpine	Mount Alexander
Buloke	Moyne
Colac Otway	Murrindindi
East Gippsland	Nillumbik
Gannawarra	Port Phillip
Glen Eira	Pyrenees
Golden Plains	Queenscliff
Hepburn	South Gippsland
Hume	Stonnington
Indigo	Strathbogie
Loddon	Surf Coast
Mansfield	Towong
Maribyrnong	West Wimmera
Melbourne	Whittlesea
Mitchell	Wyndham
Moonee valley	Yarra
Moorabool	

Note: Several new centres are currently being developed, for example in Whittlesea.



Victorian Equal Opportunity
& Human Rights Commission

Contact us

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Email	information@veohrc.vic.gov.au
Website	humanrightscommission.vic.gov.au