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# **Complementing or conflicting human rights conventions? Realizing an inclusive approach to families with a young person with a disability and challenging behaviour**

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# Complementing or conflicting human rights conventions? Realizing an inclusive approach to families with a young person with a disability and challenging behaviour

## **ABSTRACT**

United Nation's conventions exist to help facilitate and protect vulnerable people's human rights: including people with disabilities (Convention on the Rights of Persons with Disabilities, 2006) and children (Convention on the Rights of the Child, 1989). However, for some families where a family member has a disability, there may be inherent conflicts in meeting stand-alone human rights' conventions. These conventions should work together to ensure that young people with disabilities and challenging behaviour and their parents and siblings all have equal rights to full participation in social, economic and civic life. Yet service system deficits mean that this is not always the case. This paper argues that governments need to provide a whole of family and community support approach to ensure the human rights of all family members are met. This is a complex ethical, moral and human rights issue that needs addressing by disability scholars and the disability community.

**Keywords:** human rights; young people with disabilities; challenging behaviour; family; community

## **POINTS OF INTEREST**

- Young people with disabilities and challenging behaviour have important human rights that need to be protected.
- The siblings and parents of these young people also have human rights that need to be protected.
- The different sets of human rights for each group do not always work together.
- Sometimes services for the young people are not adequate and do not take account of the needs of the whole family.
- Governments must deliver services to realise the human rights of all the people in the family.

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## **Introduction**

The UN Convention on the Rights of Persons with Disabilities (CRPD 2006) aims ‘to promote, protect and ensure’ the full rights of people with disabilities. Living in and being included in the community is a key part of the CRPD (Article 19), making social inclusion and community living not only socially just, but also a legal right. By early 2010, 143 countries had signed the CRPD. Yet, without adequate community-based supports and services, the rights espoused in the CRPD may not be realized for young people (12-24 years) with disabilities and challenging behaviour. Challenging behaviour is defined as ‘culturally abnormal behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to limit use of, or result in the person being denied access to, ordinary community facilities’ (Emerson 1995). This definition shows that where inadequate supports are provided, the rights of the person with the challenging behaviour are unlikely to be met. Furthermore, the rights of the parents and siblings of young people with disabilities and challenging behaviour, as outlined in the Universal Declaration of Human Rights (UDHR 1948) and the Convention on the Rights of the Child (CRC 1948), might also be contravened. In theory, the CRPD and other human rights conventions should work together to facilitate the equal rights of young people with disabilities and challenging behaviour, their parents and siblings to participate in social, economic and civic life. In practice, however, this is not always the case.

This paper examines the quandary of competing human rights and attempts to provide a framework for a more inclusive approach to ensure that all family members’ rights are met. It builds on literature in the areas of human rights law and the social

inclusion and wellbeing of people with disabilities and their families. There is a significant body of literature on international human rights law and on the specific conventions. Much has been written on the CRC (Van Beuren 1998; Verhellen 2006) and there is a growing literature on the CRPD (MacKay 2007; Kayess and French 2008). Researchers in Australia and elsewhere have also explored the social exclusion of people with disabilities (Susinos 2007; Knight et al. 2009; Muir et al. 2009) and the high prevalence of violence they experience (Brown and Craft 1989; Muir et al. 2009; Sherry 2010). There is also a body of literature focusing on the wellbeing of families with children with disabilities in Australia (Gray and Holden 1992; Llewellyn et al. 2003; Burton-Smith et al. 2009) and elsewhere (Hastings 2002; Heller and Caldwell 2006) and on supports for parents of children with disabilities and challenging behaviours (Gavidia-Payne and Hudson 2002). Work completed thus far deals with specific conventions or the needs and interests of specific groups – either people with disabilities or their families. It seems, however, that the issue of conflicting needs in relation to the human rights of the whole family unit is underdeveloped in the human rights and disability literature.

This article begins to address this gap by applying a human rights framework to a whole of family approach where a child or young person has a disability and challenging behaviour. It will do this by: identifying key similarities to social, economic and civic rights within the CRPD and UDHR; examining the extent to which the rights of people with disabilities and their family members are being met in Australia; and, using ecological and relational rights theories, inform how society may be able to move forward to realizing the rights of all family members. This paper argues that governments need to provide a whole of family and community support approach to ensure that the UN human rights treaties complement, rather than

compete with, each other. This is a complex ethical, moral and human rights issue that needs to be debated and addressed by disability scholars and more broadly in the disability community. Without an appropriate approach, countries will struggle to meet the CRPD and other rights of a group of young people and their families.

### **Social, economic and civic rights within the CRPD and the UDHR**

International human rights law provides the framework for state action in meeting the needs of all its citizens. Both the UDHR and the CRPD cover social, economic and civic participation, giving ‘all people’ (UDHR) and specifically people with disabilities (CRPD) the legal right to full participation in society.

The UDHR entitles the family to protection by society and the State (Article 16(3)); provides a right to social security (Article 22); a right to work (Article 23); a right to rest and leisure (Article 24); a ‘right to a standard of living adequate for the health and well-being of himself and of his family’ (Article 25); a right to education (Article 26) and a right to freely participate in the cultural life of the community (Article 27).

Similarly, the CRPD provides a right to respect for home and family life (Article 23); a right to work on an equal basis with others (Article 27); a right to participation in cultural life, recreation, leisure and sport (Article 30); a right to the ‘enjoyment of the highest attainable standard of health without discrimination on the basis of disability’ (Article 25); a right to an adequate standard of living for themselves and their families (Article 28); a right to education without discrimination on the basis of equal opportunity (Article 24) and a right to live independently and be included in the community (Article 19).

Thus the CRPD and the UDHR call for similar rights for ‘all persons with disabilities’ (CRPD 2006) and ‘for all peoples and all nations’ (UDHR 1948). These

conventions provide the right to family, work, rest and leisure, a standard of living, education and participation in the community for all family members. But to what extent are these rights being met?

### **Realisation of the rights of people with disabilities and the rights of family members**

There is not sufficient data to understand the extent to which each of the individual rights of people with disability and challenging behaviour and the rights of their family members are being met. However, looking over the last decade there is data to assess whether the rights of Australians with disabilities and the rights of family members who are carers were met in regard to education, work, rest and leisure, a standard of living and participation in the community in recent years. Where available, data on young people (12-24 years) with disabilities is used.

#### ***Education and work***

People with disabilities and family members were less likely to be realizing their right to education than people who did not identify as having a disability or people who did not identify as family members of a person with a disability. In 2003 15–64-year-olds with a profound or severe disability (living in households) were less likely to have completed Year 12 than people without a disability (24% and 49% respectively) (ABS 2004). They were also less likely to have a diploma or a higher education (14% and 28% respectively) (ABS 2004). Family members of people with disabilities had lower levels of Year 12 completion or equivalent (ABS 2008), which may be a result of not having the time to re-engage in education because of caring responsibilities.

Similarly, people with disabilities and family members of people with disabilities were much less likely than their counterparts to be realizing their right to work. In 2003 15–64-year-olds with a profound disability were more than five times less likely to work than people without a disability (15% and 81% respectively) (ABS

2004). This is clearly not on an ‘equal basis to others’ (Article 27, CRPD). While the gap was not as stark, in 2008 family members of people with disabilities were less likely to be employed than other family members (73% compared to 63%) (ABS 2008). If people with disabilities and their family members were employed they were more likely to be working part-time than full-time (ABS 2004; ABS 2008).<sup>1</sup>

### ***Standard of living***

With lower levels of education and employment, it is not surprising that the right to an ‘adequate standard of living’ was less likely to be met for people with disabilities and their families, compared to their counterparts. People with disabilities were less likely to have wages or a salary as their primary source of income (23% and 57% respectively) (ABS 2004) and their weekly median gross personal income was less than half of that of people without disabilities (ABS 2004). While the gap was smaller, on average family members of people with disabilities earned between 25-30 per cent less than other family members (Bittman et al. 2007; ABS 2004; Cummins 2007). In 2005 Access Economics estimated that parents of children with disabilities lost \$4.9 billion of income per year through lost wages (2005). They also had a lower level of satisfaction with their standard of living (ABS 2004; Cummins 2007). In addition to the lower income, it can cost two to three times more to raise a child with a disability (Dobson et al. 2001).

### ***Participation in leisure and the community***

The right to participation in leisure was less likely to be realized for young people with disabilities and for family members who are carers. Young people with disabilities between 15-24-years reported poorer social support and were less satisfied with spare time activities (Emerson et al. 2009); they were less involved in decision making in schools, the community and government (Bell et al. 2008); and they spent

an average of three fewer hours per week with friends (Muir et al. 2009) than other young people without disabilities.

The participation of family members in the community was an area where their rights were more likely to be met. Family members of a child with a disability were more likely than other family members to volunteer (45% compared to 31%), lobby services (35% compared to 22%), and participate in community events (ABS 2008). They were also more likely to have been active in social and community groups, community support and civic activity (including advocacy) (ABS 2008). While both groups of family members had similar face-to-face contact with family and friends, 35 per cent of family members of a person with disabilities reported losing touch with or changing their friends (ABS 2008).

### ***Health and wellbeing***

Evidence also shows that Australia has not met its responsibilities in regard to health and well-being for young people with disability and their family members. Young people with disabilities were more likely to have poorer mental health (Honey et al. 2009), to feel unsafe and to have substance use disorders (Muir et al. 2009), than young people without disabilities.

Although one in four primary family members of people with disabilities (26%) felt satisfied as a result of their caring role in 2003, one in three (34%) felt weary or lacking in energy (ABS 2008). Other research found that parents of a child with a disability were more likely to experience stress, have lower levels of marital satisfaction and poorer mental health than other families (Gardner and Harmon 2002:61; Patterson 2002:356). It is unsurprising then that family members of people with disabilities fare poorly when their wellbeing is compared to others. Using the Personal Wellbeing Index, Cummins (2007) found that family members of people

with disabilities had ‘the lowest collective wellbeing of any group’ researched over the past 6-years in 17 Australian population surveys.

### ***Safety***

An important part of maintaining health and wellbeing is the capacity to remain safe from physical harm. This may not necessarily be the case for young people with disability and especially for young people with disabilities with challenging behaviour and their family members. Young people with disabilities’ in general are more likely to be victims of a violent crime (Muir et al. 2009). For young people with disability and challenging behaviour, their behaviour by definition is ‘of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy’ (Emerson 1995). Carter’s (2006) enquiry into challenging behaviour found that the behaviours, such as ‘aggression, destructiveness, self-injury, consuming inedible objects, non compliance, persistent screaming, regurgitating food and smearing faeces on property or person’, ‘have potentially serious and damaging consequences for the person him/herself, family, other carers, others with intellectual disability and at times members of the community’. Thus, if adequate support is not provided, the young person with the disability, their parents and siblings may be at risk of exposure to violence and other behaviours that may compromise their safety, health and wellbeing.

For the young person with the disability and their siblings this directly contravenes Articles 3 and 19 of the Convention on the Rights of the Child. These Articles ‘undertake to ensure the child such protection and care as is necessary for his or her well-being’ (Article 3) and ‘to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation... while in the care of parent(s), legal guardian(s) or any other person’

(Article 19). Failing to provide adequate support to protect a young person with challenging behaviour from self-injury and abuse also contravenes Article 16 of the CRPD, which requires governments to ‘take all appropriate measures to prevent all forms of exploitation, violence and abuse’. A mother who is experiencing violence from her child with a disability with challenging behaviour is also having her rights to personal security compromised.<sup>2</sup>

Thus while young people with disabilities and challenging behaviour are afforded the same rights as their family members, in very few cases have the rights of people with disability or family members actually been met. The system has failed to realize the rights of either group. So how does society balance meeting the rights of different family members?

**Do the rights of the individuals within families compete or complement each other?**

Different human rights conventions should complement each other in providing for the full set of rights of those covered by them. A principle of human rights law is that rights are interdependent, indivisible and interrelated hence different rights should be understood as operating together to meet the comprehensive needs of rights holders. In fact, there are often overlaps with groups of rights holders as people face multiple disadvantages, for example, women with disabilities.

In theory, protecting, respecting and fulfilling the rights of a young person with a disability with challenging behaviour, his parent(s) (often the primary carer is the mother) and his siblings is a complementary project of meeting each family member’s needs in respect to each other. The CRPD, for example, refers in its preamble (section c), to the ‘universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms’. This restatement of a principle of international human rights law requires rights to be followed with

reference to all other rights. The CRPD also specifically acknowledges the other UN Conventions. But rights claims do sometimes lead to competing demands by two sets of disadvantaged groups. Case study examples make the quandary obvious.

A study that interviewed the parents of nine teenagers with intellectual disability and challenging behaviour attending a school for this group of young people, found that the families experienced ‘challenging behaviours to a dangerous level to themselves and other family members’ (Green et al., np). The report went on to explain that ‘current supports fail to maintain the safety of family members’.

The mother of three children described at a public forum on young people with disability and challenging behaviour that she wrote bedtime stories for her two younger children that explained how and where they could hide in an attempt to keep them safe from their brother with a disability and challenging behaviour. The family’s experiences were further described by their mother. At 3-years-of-age one of the siblings, James<sup>3</sup>, asked: ‘Why does [Michael] hit me?’ By the time James started school he had inadequate social skills and was bullied and beaten up. James has had extensive counselling to assist him to deal with the thought that he was ‘not brave enough, strong enough or good enough’ to protect his mother while Michael was hitting her. James and Michael’s sister, Sarah, ‘has been grabbed, pushed, kicked [and] pinched’ by Michael and has had consequent broken bones and a split lip. She too has had counselling, where she described her brother as a ‘scary monster’. Sarah’s mother says that Sarah has poor social skills, difficulty negotiating conflict with her peers and she still ‘hides under beds, in cupboards, behind doors, under tables’ when she is confronted with something that worries her, despite the fact that Michael no longer lives in the family home. Now that Michael is in full-time residential care in the community, his mother believes he is happier because the care environment can

provide 'a very structured life'. For her, Michael is now 'a joy to be around' and Sarah, James and Michael spend time together in a highly organised, structured way on the weekend. For the first time, the children play together. In their mother's words, James and Sarah now 'have the opportunity to form a relationship with him based on love and happiness instead of fear and loathing'.<sup>4</sup>

This families' story provides a clear example of where individual rights of different family members can come into conflict. Michael's right to remain in the family home as outlined in the CRPD was contravened by his placement in full-time residential care. Sub-articles 3 and 4 of Article 23 of the CRPD were not followed. He did not have 'equal rights with respect to family life' (3), he should 'not [have been] separated from his ... parents' unless it was in *his* 'best interest' (4). However, while he remained in the family home, the right of James and Sarah to be 'protect[ed] from all forms of physical or mental violence, injury or abuse ... while in the care of parent(s)' (Article 19, CRC) was continually breached, despite their mother's attempts to keep them safe. The subsequent psychological problems experienced by both James and Sarah provide evidence that their right to 'protection and care as is necessary for his or her wellbeing' (Article 3, CRC) was also contravened. So which rights should be met? Michael's under the CRPD or James and Sarah's under the CRC?

The second example is of a family with two children with physical disabilities, Sophie and Jacob. Sophie, who has a physical disability, goes to a mainstream high school, while Jacob attends a boarding school for teenagers with intellectual disability and challenging behaviour. He comes home on the weekends and during the school holidays. As a result of the boarding school placement, Jacob and Sophie's mother was able to attend university and obtain a degree and she is able to work full-time and maintain a level of community and social involvement during the week. On the

weekends the family remains within the home because they do not have adequate support for Jacob's challenging behaviour to enable them to socialise or take part in the community. While the family has some balance as a result of the boarding school, the parents find it difficult to keep Sophie safe on the weekends from Jacob's violent behaviour. They are also trying to keep Sophie safe from sexual assault, as Jacob goes through puberty. At the end of 2010, the boarding school will be closed because it contravenes government policy about integration and the right of the child to live in the community. This will realize Jacob's right to live in the family home, but if adequate support is not provided, it will contravene Sophie's right under the CRPD and CRC to live in a safe environment free from physical violence and sexual assault, their mother's right to work, and the whole families' right to participate in the community and have periods of rest and leisure. If their mother's question, 'How can I keep [Sophie] safe?' cannot be answered, it is likely that the family will relinquish care for Jacob to the State. The latter would contravene his right to live with the family.<sup>5</sup> If this were to occur, Jacob would be far from alone. In a study by Llewellyn et al. (2003), over one-in-four parents of 6-13-year-olds with disabilities had sought or seriously considered alternative residential/out-of-home care for their child.

In the words of Jacob and Sophie's mother, these families 'are ordinary people with an extraordinary task' and they do not receive the support they require to meet the rights of any member of the family, including the young person with disabilities. Again, whose rights should be met: Jacob's or Sophie's? Should the rights of one child be prioritised over another? These questions raise very serious and complicated legal, moral and ethical issues. From a legal perspective, the best interests of the child with the disability and the best interests of the sibling (also a child) are both 'paramount' in international human rights law (CRPD Article 7 and CRC Article 3).

Therefore in situations where there is a potential conflict between the rights of each child, a balancing process needs to occur to weigh up the rights of each person, reasonable limitations on each of their rights, and a solution that maximises the rights of all people involved. There are no simple legal formulas for achieving such a balance.

As a society, we should not be in a position where we have to ask the question, ‘Which child’s rights do we prioritise?’ The fact that we have case studies where conflicting rights occur demonstrates a serious deficit in the service system. So how do we move forward? How do we ensure that human rights conventions ‘speak’ to each other in addressing the needs of all disadvantaged groups by taking into account the rights of each other?

### **Moving forward: a framework for the inclusion of all family members**

There is value in trying to develop a framework that can inform both adjudicative processes and policy processes to prevent and resolve situations where the rights of one individual are conflicting with another. Two theories are drawn from to move this forward: a legal and a sociological one.

#### ***Relational rights***

From a legal perspective, relational rights is a useful concept to draw from. The idea of rights as relationships arises from feminist legal theory as developed by writers such as Minow (1990); Minow and Shanley (1996) and Nedelsky (1989; 1993; 2008). Nedelsky maintained that rights holders cannot be understood as individuals separated from the relationships of interdependence that constitute them. She suggests that rights must be informed by the relationships that people wish to foster. Nedelsky argued (1993) that rights are part of a ‘dialogue of democratic accountability’ rather than trumps, limits or barriers. Although Nedelsky’s work on rights has been

developed in relation to constitutions, her arguments are also applicable in other contexts including international human rights law (Lacey, 2003: 52). The ‘rights as relationships’ model provides a principled basis with which to resolve rights conflicts. In dealing with the right to autonomy, Nedelsky argued (1989) that what makes autonomy possible is the structuring of relationships and collective power to ensure a balance between the individual and the relationships on which they depend. She refers to the example of laws that require educators to involve parents of children with disabilities in defining the appropriate approaches to be taken regarding their children. This law addresses power imbalances and leads to constructive consultation rather than contests between parents and teachers. Its focus on process and outcome avoids some of the conflicts that an individualistic approach to rights entails. Nedelsky (2008: 141) sets out three steps for the relational approach:

The first is to examine the rights dispute (e.g., competing interpretations, advocating change in traditional meaning, debating what the list of constitutional rights should be) to determine what the values at stake are. The second is to ask what kinds of relationships would foster those values. The third is to determine how competing versions of a right would structure relations differently.

The ‘rights as relationships’ approach requires a great deal of attention to context and the changing meaning of values within different contexts. This approach can be used to deal with the competing rights claims under international human rights law as discussed in this paper. The rights dispute – for example between the right of a child with a disability to live at home and the right of his sibling to live free from violence – should be understood through a relational lens. If the individual rights are pitted against each other, it is easy to lose sight of the values at stake and the relationships those values ought to foster. Viewed relationally, the values of family, freedom from violence and *state support* for individuals and families in need lead to considering alternative and constructive approaches that might emphasise a whole of family approach with stronger state assistance over more individualistic and

adversarial models. This approach is also useful because it correctly takes the problem away from the person with the disability.

### ***Ecological model***

From a sociological perspective, it is useful to draw from Bronfenbrenner's (1979) ecological model of child development. He argues that a child's development is determined by the social context within which it lives. The child is situated within the family and the community. Its development is influenced by his/her social contexts of micro-systems (the family, school and peer group), meso-systems (connections between micro groups), exo-systems (community) and macro-systems (societal structures, cultural values, policies and laws). While Bronfenbrenner's theory has largely been used by early childhood development scholars, the family and community remain strong influences on adolescents. Children with and without disability are no different; they live and are affected by the social context within which they live. Thus the family and community are of substantial influence in addressing the rights of the child. This same concept applies to siblings without disabilities and to parents. The whole family and community must be considered in attempting to meet the needs of each individual family member - they cannot be addressed in isolation.

The relational rights theory and ecological model are both useful concepts in establishing a framework that works towards meeting the needs of all family members. They demonstrate that a whole of family approach may be beneficial.

### ***A whole of family approach, the Universal Declaration of Human Rights and the CRPD***

A whole of family approach is supported when the foundations of the UDHR and the CRPD are closely examined. Even though most of the rights in the UDHR and CRPD apply to individuals, Article 16(3) of the UDHR says that the 'family is the natural

and fundamental group unit of society and is entitled to protection by society and the State'. The CRPD preamble also locates the individual with a disability with the family:

the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities (CRPD section x).

This suggests that the person with the disability must be seen within the context of a family where the rights of others in the family (women, children) must also be addressed if all family members' rights are to be protected. Given the ecological model, relational rights and the emphasis of the family in the Declaration and the CRPD, a whole of family approach makes sense. Supporting a child with a disability to live in a family is directly linked to the healthy functioning of that family and hence, the needs of the parents and other children in that family must also be met.

### **The responsibility of the state**

Human rights laws strongly and repeatedly emphasise the responsibility of the State and the State's accountability. Article 16 (3) of the Declaration states, 'The family is entitled to protection by society and the State'. Similarly, the preamble of the CRPD outlines, 'persons with disabilities and their family members *should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities*'. Article 23 (3) of the CRPD goes on to say that '*States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families*' (authors' emphases).

General Comments made by the Committees responsible for each individual Convention, as a guide to interpreting the rights within the Conventions, also outline the role of the State. For example, General Comment No.9 on 'The Rights of children

with disabilities' (CRC 2006) states: 'Children with disabilities are best cared for and nurtured within their own family environment *provided that the family is adequately provided for in all aspects*'.<sup>6</sup> This section of the General Comment gives detailed direction on the role of states in supporting families of children with disabilities and gives recognition to the roles of parents and siblings. Similarly, General Comment No.4 on 'Adolescent health and development in the context of the Convention on the Rights of the Child' (CRC 2003) says:

States parties must take all appropriate legislative, administrative and other measures for the realization and monitoring of the rights of adolescents to health and development as recognized in the Convention. To this end, States parties must notably fulfil the following obligations:

(a) To create a safe and supportive environment for adolescents, including within their family...;

(i) To implement measures for the prevention of mental disorders and the promotion of mental health of adolescents.

This General Comment applies both to the rights of adolescents with disabilities and mental disorders and siblings of children with disabilities who may themselves be at risk of mental health problems within families if there is inadequate support.

There is, therefore, ample support within the various international human rights instruments and commentary for the rights of the whole family where a family member has a disability. Individually and collectively, family members have the legal right to access state resources to allow them to participate as full citizens in society. Arguably, these are positive rights requiring the state to ensure that the family is supported in fulfilling its important social function. In the specific example of families where a young person has a disability and challenging behaviour, these young people have specific educational, care and other needs that require state support; they are part of families where parents similarly need support to play their own role in providing the best possible care; and their parents require state support to fulfil their responsibilities towards providing a secure, safe and stable environment for other children in the family. Where the state fails to provide the assistance it ought to,

serious human rights violations may be suffered by one or more of the family members.

In a functioning system where the state is providing the appropriate support to the family, problems should not arise. It is when there is inadequate support, that family breakdown can lead to conflicts between the rights of family members – in this case, the young person with the disability, the parent and the siblings.

### ***Gaps in the service system***

The failure to meet the human rights of people with disability and their family members and the case studies provided, illustrate that there are deficits in the Australian service system. This is further reinforced by evidence found within independent research, government reports and the media. Carter (2006), in his enquiry into families with children with disability and challenging behaviour, found that ‘it is generally beyond the capacity of the family, despite heroic effort, to cope into the longer term; they desperately need access to the resources of government to be able to deal with it [challenging behaviour]’. The Australian Government’s *Shut Out* report (2009) stated that the ‘disability service system was characterised as irretrievably broken and broke, chronically underfunded and under-resourced, crisis driven, struggling against a vast tide of unmet need’.

Peak groups, such as National Disability Services (2009), call for further funding and services. Numerous media articles also report substantial gaps in the service system, high levels of parental stress and the consequent placing of children in state care (Corrigan 2009; Guest and Neal 2008; Carlisle 2010). And while the literature on deinstitutionalisation generally finds positive outcomes (Mansell, 2006:67; Institute for Family Advocacy and Leadership Development 2007), it is also acknowledged that the money saved was not always redirected to the community

(Ozdowski 2001) or invested to meet individual needs (Bain 1998; Bigby and Fyffe 2006).

An ongoing challenge will be ensuring that developed countries like Australia invest sufficient resources to meet the CRPD. It is important that these countries do not avoid their obligations by arguing that they do not have the resources to do so. All states under the Convention are required to ‘progressively realize’ the rights in the Convention (Article 4(2)) and wealthy countries would be hard-pressed to claim that they are not yet able to begin meeting these goals. Unless a whole of family approach is used, States will fail to meet these rights in the situation of families where a child has disabilities and challenging behaviours.

### **Conclusion**

Human rights laws exist to protect people, particularly those from vulnerable groups, such as people with disabilities and children. Drawing on data over the last decade, this article has demonstrated that Australia has largely failed to meet the social, economic and civic rights of both people with disabilities and their families. And, using case studies of young people with disabilities and challenging behaviours, it has shown that while human rights laws should theoretically work together, without adequate supports, the individual rights of different family members can conflict and contradict each other. If countries like Australia are going to realize the rights of young people with disabilities and challenging behaviours and their family members, as outlined in the CRPD, CRC and the UNDHR, then a new framework may be required. This article offers a way out of this potential conflict. It argues for a focus on relational rights, or the interdependence of rights, and it emphasises the importance of using an ecological approach – looking at young people with disabilities and challenging behaviours within the context of their families and communities. Most

importantly, it reinforces the responsibilities of the State in providing a whole of family approach within a human rights framework. Put simply, in a well functioning system where the State provides appropriate support, the rights of all family members should be met. Given Australia's and other countries' ratification of the CRPD, change in this area is not just a social and moral imperative, but also a legally binding one.

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<sup>1</sup> Note all data is based on the 2003 Survey of Disability, Ageing and Carers. Results were released at different times.

<sup>2</sup> Under the UDHR, the ICCPR or in terms of the 'Declaration on the Elimination of Violence against Women' General Assembly/RES/48/104, 85th plenary meeting, 20 December 1993.

<sup>3</sup> All names have been changed to protect the identity of the children and their family.

<sup>4</sup> Public forum, April 2010, and a conference paper by the children's mother, February 2010. The specific details have been withheld to protect the family's identity.

<sup>5</sup> Public forum, April 2010; further details have been withheld to protect the family's identity.

<sup>6</sup> Authors' emphasis.