Disability and social rights: Family and intimate relations

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This chapter discusses Article 23 of the Convention on the Rights of Persons with Disabilities (CRPD), Respect for home and family. It builds on previous work that has provided empirical and conceptual evidence on the sexual and reproductive rights of disabled people (Shakespeare et al 1996, Shakespeare 2006). The reason for doing this work is that for many people, disabled and non-disabled alike, having a relationship and forming a family are key ambitions in life, alongside getting a job. Sex is not a secondary issue. If disabled people are to achieve full acceptance and inclusion in society, then relationships and parenting must become accessible to them on the same basis as others. For example, in many developing countries, to be someone, you must have a family.

Research and advocacy in this area has been sparse. It is easier to work on issues such as health, education, employment and living in the community than it is to work on the issue of relationships and parenting (Finger 1992). In some traditional cultures, e.g. South Asia, sexuality is likely to be a taboo subject for everyone, let alone for people with disabilities. In many cultures there are very negative assumptions about people with disabilities as prospective husbands, wives and parents, together with even more negative assumptions about same sex relations. Attitudinal change is a key part of ensuring Article 23: attitudes of parents and professionals, attitudes of people with disabilities themselves, and attitudes of their prospective sexual and romantic partners.

Enabling people to feel positive about themselves, and enabling non-disabled people to feel positive about them, reflects wider processes of empowerment and cultural change. The more people with disabilities achieve their other civil and social rights, the more they will have the confidence, self-esteem and desirability that make relationships possible. For example, without an education or a job, you may lack money and you may lack cultural capital, and you may lack a rich network of friends (Shakespeare et al 1996, Shakespeare 2006). If you are confined to an institution, or cannot access your community because of physical barriers, then you will find it hard to meet prospective partners. All other CRPD Articles therefore are supportive of Article 23, achievement of which is therefore effectively one of the key outcome measures for the whole endeavor.

Sexual and reproductive rights and the CRPD

It has been said often that the CRPD creates no new rights, but merely extends and reinforces existing rights for a population, disabled people, who have been historically denied them. This makes it relevant to look at the broader human rights tradition of respect for marriage and family, which are social rights that go beyond classical civil liberties (Tomlinson and Shuckla 2001).

Article 10 of the International Convenant on Economic, Social and Cultural Rights (UN 1966a) necessitates protection and assistance to the family, as the "natural and fundamental group unit in society"; it requires free consent of intending spouses to marriage; it offers special protection to mothers before and after childbirth; and it highlights the importance of special protection for children, particularly from economic and social exploitation. Article 10 of the ICESCR echoes Article 16 (family) and Article 25 (children) of the Universal Declaration of Human Rights. It is also relevant to note that while Article 12, on the right to health, does not specify access to sexual and reproductive health, General Comment 14 (Committee on Economic, Social and Cultural Rights 2000, paragraph 34) interprets the ICESCR as promoting sexual and reproductive health.. Article 23 of the International Convenant on Civil and Political Rights (UN 1966b) again asserts the primacy of the family and the need for society and the State to protect it. The right to marry and found a family, with free and full consent. In the European Convention on Human Rights, Article 8 treats respect for family life and Article 12 protects the right of marriage. In all these Conventions, family rights are treated as part of general privacy rights. Whereas civil rights are stated as firm duties and obligations, these types of economic, social and cultural rights are softer goals, which are harder to guarantee:

> "People have rights and governments have duties in regard to civil and political rights; in contrast, people have economic, social and cultural rights, but treaties do not insist that governments have strong obligations to fulfill those rights." (Haas 2008, 139)

Legal debate around the rights to marriage and family life has turned on the relative rights of mothers versus fathers, and the question of abortion and involuntary sterilization (e.g. New Zealand Re X, 1990). It has included residence permits for spouses and the issue of same sex marriage. Cases have also concerned state interventions for the welfare of children (Tomlinson and Shukla 2001). While all these issues, particularly sterilization and child welfare, will potentially be relevant to disabled people, they have generally turned on cases where marriages and families are in existence, and the debate is how they are to be regulated. In disability, a fundamental issue is whether disabled people can access the same possibilities of relationships and reproduction that others take for granted.

Turning to the CRPD, Article 23 requires States Parties to

> "take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others"

Here it is relevant to remember that the CRPD specifically states that denial of reasonable accommodation constitutes discrimination.

Article 23 goes on to specify the right to marry and found a family on the basis of free and full consent of intending spouses; to decide freely and responsibly on the number and spacing of their children to have access to age-appropriate information, reproductive and family planning education; and to have access to "the means necessary to enable them to

exercise these rights". Persons with disabilities have the right to retain their fertility on an equal basis with others, although a reference to forced sterilization was removed during drafting. Persons with disabilities shall have the same rights with regard to being guardians and to adopt children, with the best interests of the child being paramount. Very importantly, State Parties shall "render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities".

The remaining clauses of Article 23 concern the equal rights of children with disabilities to family life: despite the importance of these issues, the requirement to focus the chapter means that the discussion will concentrate on the reproductive rights of adults, rather than the family life rights of children with disabilities. In relation to these rights, it is also relevant to mention Article 25, Health, which specifies that State Parties shall provide the same range, quality and standard of free or affordable health care to disabled people as to nondisabled people, "including in the area of sexual and reproductive health and population-based public health programmes".

From this presentation, it appears that CPRD goes considerably beyond ICESCR in specifying the sexual and reproductive rights that should accrue to disabled people, although it is less detailed than Rule 9 of the *UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Article 23 still falls short of specifying that some disabled people require support and protection to express same sex desires and achieve non-heterosexual relationships. The emphasis is very much on marriage and heterosexual reproduction, perhaps due to the influence exerted by the Holy See and other conservative states during the drafting of the CRPD. However, the stated outlawing of discrimination against disabled people in "parenthood and relationships" should surely be interpreted as covering all forms of parenting and all forms of relationships.

As well as the distinction drawn above between classical civil liberties and the new generation of social rights, Anderson and Philips (2012, 1) highlight how the CRPD demonstrates that human rights protections are not just about negative rights - prohibiting interference with individuals - but require active measures to promote positive rights. Article 23 (and 25) contain both negative rights – freedom from restrictions of marriage and sexuality – and also positive rights – such as the right to sexual and reproductive information and education and reproductive health services, and the right to support with parenting. Harnacke and Graumann (2012) trace Article 23 back to the International Convenant on Civil and Political Rights. But whereas in traditional human rights law this was a negative right – protection from interference, such as protection against involuntary sterilization – they emphasize how the Convention on Rights of Persons with Disabilities also places duties on States to support disabled parents, thus creating positive rights. They conclude that this right is "posing one of the greatest challenges following from ratifying the Convention (2012, 42).

Thus Article 23 goes to the heart of the classic distinction between first generation rights – also called negative rights or liberty rights – which require state to abstain from interference, and second generation rights – also called positive rights or claim rights – which require adequate standard of living:

> "A positive right is a claim to something – a share of material goods, or some particular good like the attention of a lawyer or a doctor, or perhaps the claim to a result like health or enlightenment – while a negative right is a right that something not be done to one, that some particular imposition be withheld." (Fried 1978, 110)

The distinction between negative and positive rights can be overdrawn (Van Weele 2012, 25) – after all, government intervention is needed to achieve regulation protecting negative rights, and the positive right to parent requires, for example, that government social services desist from removing children unfairly from their birth families. In the area of disability, in particular, positive action is often required to ensure negative rights, such as physical and information access improvements to enable disabled people to vote or get a fair trial. Because the CRPD combines positive and negative rights even within Articles (Degener 2013), interpretation of the implication and meaning of Article is often needed (Harnacke and Graumann 2012, 47). What Degener calls the human rights model of disability contains both political/civil and social/economic rights (Degener 2013).

Finally, it is also important to return to the purpose of the CRPD, outlined in Article 1, which is to "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities". This language is slightly different from the "respect, protect and fulfill" language of the ICESCR, but it amounts to much the same triple responsibility upon States: they should not interfere with the enjoyment of rights; they should prevent others from interfering with the enjoyment of rights; and they should play a facilitating and promoting role to ensure that people can enjoy those rights. These obligations will be relevant when it comes to achieving the Article 23 goals of access to sexual and reproductive and family rights for persons with disabilities.

Evidence about disability and sexuality

Discussions of disability and sexuality almost always highlight the prevailing attitude that disabled people are asexual. This is part of the ludicrous but long-standing prejudice that impairments are incompatible with sexual desire and sexual activity. Negative attitudes are a major part of the problem which disabled people face when they wish to become sexually active or wish to become parents. However, despite the strength of what some people describe as a taboo, it is hard to say that disabled people are desexualized, when there is widespread evidence that disabled people are having sex in great numbers. For example, empirical studies show that young people with disabilities are sexually active in similar ways to people without disabilities (Brunnberg et al 2009). In fact, large Swedish studies report an earlier age of sexual debut for adolescents with modest disabilities than their nondisabled peers: 57% of girls with disabilities, as opposed to 43% of nondisabled girls had had sex, and 39% of disabled boys, versus 37% of nondisabled boys (2007 study of 15-16 year old participants in mainstream education, n=2839): it was even higher for girls (60%) and boys (50%) with two or more disabilities (Brunnberg et al 2009). The researchers connect this early sexual debut to the young disabled person's battle to be included and accepted. It was also associated with use of alcohol, tobacco, truancy. For

some people, early debut was a consequence of abuse, a factor also reported among Deaf people in the Philippines (Gomez 2011).

Disabled adults are less likely to be in partnerships, but the disparity is not huge (Trani et al 2010). Emens highlights US data showing that around 50% of people with severe disabilities, 60% of people with non-severe disabilities and 68% of nondisabled people are married (Emens 2009, 1326). Many groups within the disability population are unlikely to face significant barriers to sexual activity and partnership, for example Deaf people who associate through Deaf clubs and other Deaf subculture. Equally, disabled people are of course heterosexual, bisexual, lesbian and gay and transsexual, in much the same ways as nondisabled people (Bedard et al 2010), as we also found in our 1996 study (Shakespeare et al 1996).

Data on comparatively high rates of sexual activity may be misleading, however, insofar as they include people who are already married who become disabled, for example as they grow older. After spinal cord injury, for example, evidence suggests that the majority of women – three quarters in a Swedish study by Kreuter et al (2008) – have sex within six months post injury. A Malaysian study of women with spinal cord injury noted that 40% of the women continued to have sexual activity after injury, although there was a decline in the frequency of sexual intercourse (Othman and Engkasan 2011).

The situation may be different for those who are born with impairments. People with disabilities are more likely to live with their parents, or in developed countries to live alone, than to live with partners and have children. In the research my team conducted with people with restricted growth in Northern England, 47% of respondents were single, compared to 30% of the general population, while 41% were married or in a long term relationship, compared to 60% of the general population. The situation is likely to be comparable or worse for people with congenital impairments that substantially limit communication or independence. For some groups, social barriers may impede their ability to achieve a relationship: a large Spanish study with people with mild to moderate intellectual disability found that 72.9% had a partner, but 91.61% did not live with their partner, and 98% were unmarried (Arias et al 2009). Participants' experiences and aspirations regarding love were similar to those of nondisabled people, and where there were positive experiences of relationships, this contributed to emotional wellbeing.

Evidence from the developing world also suggests that many disabled people do access sexuality and reproduction. For example, a study in Sierra Leone found that disabled people were only slightly less likely to have had sex than non-disabled people (Trani et al). However, again there are suggestions that, especially for people with congenital impairments, it can be harder to access sex and relationships and parenting in non-western cultures. This is particularly the case for disabled women. Whereas men with disabilities may have a marriage arranged for them, particularly if they have assets, it can be much harder for women with disabilities to access marriage and have children (Hussain 2005). Women with disabilities may be perceived as incapable of having children, and thus less valuable. Gender and disability discrimination combines to render women with disabilities doubly disadvantaged. Cultural traditions of dowry (South Asia) and bride price, lobolo (Africa) or *Mahr* (Muslim) may operate to disadvantage women with disabilities.

More research is needed on how disabled people access sex and relationships and parenting. This research should distinguish between people who develop impairments after they become sexually active, and those who have early onset impairments. Studies should also distinguish different impairment groups, and different community or institutional settings, to track where the barriers to fulfillment of sexual and reproductive rights lie.

Committee on the Rights of Persons with Disabilities

The Committee on the Rights of Persons with Disabilities meets twice a year in Geneva, for a two week period. The role of the Committee is to receive and review the reports from States Parties to the CRPD. States Parties have to report initially within two years of ratifying the Convention, and every four years thereafter. After receiving and discussing the Report of the State Party, the Committee then issues Concluding Observations which discuss the progress and priorities for each State. There a number of Committee on the Rights of Persons with Disabilities Concluding Observations which are relevant to the issue of sexual and reproductive rights. The Committee does not seem consistently to discuss sexual and reproductive rights under Article 23, and there are several other articles that are relevant to the topic of marriage and parenting, such as Article 5, Article 12, Article 25.

The Committee has taken action to strengthen the right to get married. For example, in Concluding Observations, on Peru, the Committee calls for the State to amend domestic laws "to adequately guarantee the exercise of civil rights, in particular the right to marry, to all persons with disabilities" (Article 21 (1)(a)). (CRPD 2012, para 27). This was in response to the Civil Code which states that "deaf-mute, blind-deaf and blind-mute persons, as well as mentally handicapped persons and those suffering from mental deterioration" (CRPD 2012, 26) are not permitted to marry.

Concluding Observations on Argentina addresses the same topic of marriage rights under Article 23, noting with concern that Article 309 of the Civil Code of Argentina denies the right to form a family to some persons with disabilities, especially those who are "insane" or lack legal capacity (CRPD para 35). The Committee recommends not just amending law restricting freedom of marriage, but also a positive intervention:

> "The Committee urges the State party to amend the Civil Code to bring it into line with article 12 and article 23, paragraph 1 (b), of the Convention and to make support services to assist with the demands of parenthood available to persons with disabilities who require them." (CRPD para 36)

Discussing Article 23, Concluding Observations on Hungary go further still, highlighting that enjoyment of Article 23 rights depends not just on removal of restrictions, but also on positive measures such as support services:

> "36. The Committee notes with concern that persons with disabilities still face various financial, physical and attitudinal barriers to founding a family and that scarcity of the support services for independent living (see paras. 34 and 35 above),

> presents a de facto barrier to the full and effective enjoyment of the rights set out in article 23 of the Convention.
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> 37. The Committee calls upon the State party to take appropriate measures to enable men and women with disabilities who are of marriageable age to marry and found a family, as well as to provide adequate support services to men and women, boys and girls with disabilities to enable them to live with their families, in order to prevent or reduce the risk of placement in an institution."

In Concluding Observation on Spain, under Article 5 Equality and non-discrimination, the Committee expressed concern that disability affected parents' guardianship or custody of their children. (CRPD 2012, para 19)

The Committee has also made positive demands on States to promote the Article 25 right of access to sexual and reproductive health. In Concluding Comments on Paraguay, the Committee expresses concern at problems of information on health services, on accessibility of health services, and at "discrimination in the provision of sexual health and reproductive services." (CRPD 2013 paragraph 59), and the Committee asks the State party to remedy these problems of access, incorporating the gender perspective (paragraph 60).

Involuntary or coerced sterilization has been a key concern for the Committee, because it is the most dramatic violation of Article 23. Sterilization is an issue that has recently risen in prominence in the international disability rights and sexual and reproductive rights communities. For example, the Committee has called upon Hungary to "take appropriate and urgent measures to protect persons with disabilities from forced sterilization." (CRPD 2012, para 38). Again, in concluding comments on China:

> "22. The Committee is deeply concerned that both the State party's laws and its society accept the practice of forced sterilization and forced abortion on women with disabilities without free and informed consent.
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> 23. The Committee calls upon the State party to revise its laws and policies in order to prohibit compulsory sterilization and forced abortion on women with disabilities."

The Committee also issued a relevant Statement prior to the half day of general discussion on women and girls with disabilities (17 April 2013), adopted by the Committee on the Rights of Persons with Disabilities at its eighth session (17-28 September 2012)

> …The Committee expresses concern at the violence and abuses against women and girls with disabilities, as well as the restrictions to their sexual, reproductive and maternity rights…" (CRPD 2012)

To date, none of the other options for action under the CRPD have been implemented for issues of sexual and reproductive rights, however in future there is the possibility of individuals bringing complaints if their State is a party to the Optional Protocol to the Convention on the Rights of Persons with Disabilities. This process would have the potential to create jurisprudence with wider relevance to States parties as they implement the CRPD, although it would not be legally binding or enforceable. The Committee on

Rights of Persons with Disabilites could issue a General Comment, which would give interpretation and guidance on the rights contained in the CRPD: at the time of writing, General Comments on Article 12, Legal Capacity, and Article 8, Accessibility, are in preparation.

The State reporting system of the Committee on the Rights of Persons with Disabilities is the same as that for other Treaties such as Convention on the Rights of the Child, Convention on the Ending of All Forms of Discrimination Against Women, etc. The Treaty Body reporting process has been criticized as being cumbersome and bureaucratic, and lacking teeth (Oberleitner, 2007, 95). Despite signing up to a timetable of reporting, the majority of State Parties are late in submitting reports to Treaty Bodies. All Treaty Bodies face the problem of capacity. In their first three years of work, nine reports have been considered by the Committee on the Rights of Persons with Disabilities, which has the highest backlog of the Treaty Bodies (Degener 2013). If the current rate of work continues, it would take 44 years just to examine and respond to the first reports of the 134 State Parties to the Convention; follow up reports from each State are due every four years.

In turn, developing countries find the process of submitting multiple Treaty reports cumbersome for under-funded bureaucracies. Concluding Observations are not enforceable, and technical assistance for States to help them implement these findings may well be unavailable. Linkage between UN technical agencies – such as WHO and ILO and UNFPA – and the Committee on Rights of Persons with Disabilities is not well developed when it comes to State reporting. Therefore it could be concluded that the CPRD remains of greater symbolic than practical value in achieving the sexual and reproductive rights of disabled people. The remainder of this paper will consider what is required for Article 23 to become a reality, and then conclude by discussing the limitations of law in promoting social rights in the private sphere.

What would promoting, protecting and ensuring Article 23 rights require of States?

The Concluding Comments issued by the Committee on the Rights of Persons with Disabilities give a general indication of actions that States should be taking in order to enable persons with disabilities to enjoy their rights to home and family.

Many of the difficulties faced by disabled people are to do with restrictions of negative liberty, in other words socially imposed barriers that can be removed. From Sweden, Julia Bahner's 2012 research gives examples of how services for disabled people are obstacles to sexual encounters. As an example she cites how special transport services could be booked to take a wheelchair user to a bar or a nightclub. However, if he then encountered a potential partner, they could not travel home with him because the regulations did not permit passengers, with the exception of personal assistants. The same barrier is encountered on accessible taxis, trams or trains where there is only room for one wheelchair user at a time.

Andrea Hollomotz and the Speakup Committee write about how people with intellectual disabilities are not given privacy in residential group settings to develop relationships or explore their sexuality. This puts them at risk, when they seek isolated places to be sexually active (Hollomotz and The Speakup Committee 2008). Similarly, in hospitals or rehabilitation centres, the need for intimacy is rarely valued, and it may be a battle to get permission for partners to stay overnight (Bahner 2012). All these regulations and services could potentially be changed.

Other forms of barrier removal that promote fulfillment of Article 23 rights include legal reform to remove discriminatory barriers to relationships and parenting, where these exist, e.g. involuntary sterilization prohibited; access to fertility services provided on an equal basis with others; accessible HIV and STD prevention information; discriminatory prohibitions on adoption removed; support workers for people with disabilities also permitted to help them in parenting roles. Training of professionals can reduce discriminatory responses to the challenges faced by parents with disabilities: e.g. negative treatment from birth attendants, social workers 'assumption that children should be automatically removed. Vigilance, understanding, surveillance, education and other interventions can reduce the risk of sexual violence and exploitation of children and adults with disabilities, thus reducing distress and risks to health, and improving the chances of having positive sexual experiences.

Current national and international judicial action – as in the Gauer v France case in the European Court of Human Rights – and legislative scrutiny – as in the Australian Senate enquiry into involuntary sterilization (Commonwealth of Australia 2013) – can put the issue of fertility control under the spotlight and help eliminate abuse. The forthcoming UN inter-agency *Statement on Eliminating forced, coercive and otherwise involuntary sterilization* will help reinforce the global consensus that sterilization should only be permitted with full, free and informed consent, and offered as part of a range of contraceptive options.

More controversially, legal change and regulation could ensure that sex workers can operate safely and offer sexual services appropriately and respectfully to people with disabilities who wish to use these, as in Netherlands, Australia, Denmark and Switzerland.

These barriers having been removed, much remains to be done to access relationships and parenting on an equal basis with others, i.e. improving positive liberty, which can defined in terms of taking control of one's life and realizing one's goals. Liz Emens (2009) sketches out a programme of actions that go beyond the State lifting formal restrictions on who can have sex or marry. She argues that the State should eliminate penalties, for example, when a person with disability loses welfare benefits if he becomes partnered to someone who is employed. Further, the State can help level the playing field, for example by ensuring that individuals get sex education or even support in developing friendship skills. Measures to remove access barriers and what she describes as designing the "architecture of intimacy" might go beyond the obvious to include audio description in cinemas and promoting visitability of private homes. Finally, Emens suggests that the state could fund positive expressions of imagery around disabled intimacy and sexuality, such as cultural activities, arts and diversity campaigns.

At least in developed countries, many people with disabilities come into regular contact with service providers, of various kinds. Service provision can either be a barrier to relationships and parenting, or it can be an empowering and enabling force. These aspects of service provision are often not taken into account in the design and delivery of services. Among possible ways forward are:

1. Education. Making services inclusive and appropriate can ensure that people with disabilities receive sex education, and where needed, friendship education and parenting education, as well as general sexual and reproductive health interventions on the same basis as others.

2. Parenting support. Promoting parenting – both for disabled parents and parents of disabled children – would rely on positive developments in service delivery which ensure that such families get the welfare benefits, the information, the personal support and the networking which might make it easier for parents to raise their children and prevent the children being abandoned. Reviewing the evidence, Feldman et al (2012) argue that comprehensive ecologically-based family interventions are required for parents with cognitive impairments (Feldman 2012). If parents with intellectual disabilities and others are given the support they need to carry out parenting roles effectively and safely, this might diminish the opposition many parents of people with intellectual disabilities have when it comes to their adult children being sexually active.

3. Expansion of personal assistance or other forms of homecare can remove or lessen the assistance and support burden from partners of people with disabilities, thereby supporting the intimate partner relationship.

Fulfilment of Article 23 requires work on other Articles of the CRPD, in particular Article 12, legal capacity. Supported decision making is very relevant to intimacy and relationships, and the vulnerability of some people with cognitive deficits makes resolving the complexities very important. More innovation and testing is required to enable people to make safe decisions (Werner 2013).

This range of expansions of negative and positive liberty is extensive. Given that the basic rights of living in the community, access to health (Article 25), education (Article 24), employment (Article 27) are not always currently ensured, it may not seem a priority to invest time and funding in promoting Article 23 implementation. However, the attention paid by the Committee on the Rights of Persons with Disabilities in their Concluding Observations sends a signal that this is regarded as a very important and neglected social right.

In implementing Article 23 and other social, economic and cultural rights prioritisation may be needed, and a sense of realism. None of the ideas outlined here appear over-ambitious, but the possibilities and timescale depend on context. Realism is important, because any State has to be capable of fulfilling obligations and a basic infrastructure is required (Gauri and Brinks 2008, 19). In many developing countries, it is fanciful to talk about sex education for non-disabled, let alone disabled, young people. The CRPD contains

the concept of progressive realization, which means that States are required to show they are moving in the right direction towards implementation, particularly of social rights.

What would implementation of Article 23 require of other duty-bearers?

Iris Marion Young (1990, 25) argued that rights are not possessions but "institutionally defined rules specifying what people can do in relation to one another." This focuses attention on the role of other duty-bearers, not just governments, in fulfilling Article 23. In human rights law, vertical rights are what citizens can expect of their governments, and this has been the focus of most of the debate around the CRPD. Horizontal rights are those duties that non state actors have towards other citizens. Arguably, particularly for social rights, these horizontal duties are in practice far more important, if disabled people are to flourish and enjoy the same rights and experiences as non-disabled people.

How might non state actors infringe Article 23 rights? Nobody has a right to sex, and it is not discriminatory to prefer one particular sexual partner over another. So discrimination does not extend to object choice. However, non state actors can prevent disabled people from enjoying their sexual and reproductive rights. One example might be when a school or teacher or parent denies sex education to a young person with disability. Another might be when a family, or residential home or support service prevents disabled individuals from developing a relationship, having sex or getting married (e.g. Associated Press 2013). Parents can perceive sexuality as a hazard for people with intellectual disability (Heyman and Huckle 1995). Foley (2012) discusses what impact Article 23 might have if parents of an adult with Down syndrome prevent them having a sexual relationship. At the extreme, when parents or doctors act to sterilize an individual without their consent, this violates Article 23, as well as Article 12. These examples seem very direct infringements of negative liberty on the part of individuals.

More indirectly, whenever people with disabilities cannot access places and contexts when sex and relationships are on the agenda, this may constitute a violation of Article 23 rights. For example, a dating agency might directly or indirectly prevent disabled people from participating in their services, perhaps by not being accessible to people with visual impairment or hearing impairment. A nightclub or bar might bar people with disabilities from entering. In these examples, it is not fanciful to suggest that an individual with disability might have a case under the CRPD against commercial entities.

Finally, disabled people's organizations and other NGOs also have a role in promoting relationships, intimacy and parenting. The disability movement has been slow to act on sexual and reproductive rights. It also has a duty under Article 23 to make services available and foster networks. After all, participation in the disability movement is one way that people can meet each other, gain confidence, and form relationships. For example, in Egypt, women with disabilities requested that their disability organization create a dating service.

Sexual and reproductive rights and the law

In conclusion, there are questions to be raised about the limits of law, and the role of law.

The CRPD has been regarded as a huge step forward, and there is a considerable expectation that it will transform opportunities for disabled people. But this may be over-optimistic. It may be more realistic to see the CRPD as part of a broader process of social and cultural change, rather than expecting the CRPD itself to generate much of that change. Law has limitations. First, in countries with a dualist legal system, simple ratification of the CPRD does not mean that it becomes part of domestic law, although it would be used to interpret domestic law. Second, there is continuing debate about how economic and social and cultural rights can be made justiciable (Gauri andBrinks 2008, Ssenyonjo 2009 346ff). Third, people would need to resort to litigation to enforce their rights:

> "To benefit from these universal mandates, individual citizens or groups must find some hook, some demand mechanism, to bring universal principles to bear on their own particular situation. Where they are active and effective, the courts have become one of many such possible mechanisms." (Brinks and Gauri 2008, 305)

Litigation requires funding and legal support, which is often unavailable. The experience of other areas of social rights is that the real work begins after the ruling, when enforcement is needed. However, often just the threat of litigation leads to modification of government behaviour or spurs action by other parties.

But law can be circumvented. In the context of involuntary sterilization, Desjardins (2012) shows how, in a country such as Canada that outlaws sterilization without consent, families circumvent the prohibition by an active process of persuading young people with intellectual disabilities that it is in their best interests to "voluntarily" opt for sterilization. Foley (2012) is pessimistic as to whether Article 23 rights can actually be applied in the face of parental moral opposition to their disabled adult child's sexual relationship. Proxy decisions have more weight than individual rights, which suggests those rights may not be rights at all.

If disability rights legislation has limits in general, then in particular law and policy are blunt and indirect instruments when it comes to relationships and parenting. As a male contributor to Shuttleworth's US sex and disability research said "The ADA will not get me laid". Part of this is because human rights discourse is focused on individuals and their demands. But by definition, intimate relationships and parenting involve third parties. Family members – partners, children, other relatives – are largely absent from CRPD. In particular, in promoting the rights of disabled people to become parents, how do we protect the rights and interests of children? Do parents of people with intellectual disabilities have a right to avoid becoming grandparents-with-care of their grandchildren? If disabled people are to have access to prostitution, or to be facilitated to have sex, how do we protect the rights and interests of sex workers and personal assistants?

Relatedly, families affected by disability can challenge the notion of family as a private sphere, just as feminist human rights lawyers have argued against the public/private split

(Degener 2013). Professionals and personal assistants are necessarily involved in many families affected by disability, and caring and helping tasks are broadened beyond a mother and a father or a partner. An over-individualized approach to the issue of relationships and parenting obscures the realities of inter-dependency. Historically, sexual rights activists have sought to keep the law out of their bedrooms. There is a delicate balance to be achieved between surveillance and support, and freedom and privacy. State intervention can be enabling and disabling, and people with disabilities have reasons to be cautious about asking for help from services that are often discriminatory. Equally, the freedom to have sex and relationships also means a greater likelihood of encountering the risk of abuse and heartbreak: people can to a certain extent be protected against the former, but not the latter.

Some commentators on social rights have questioned whether it is problematic to see human rights only in terms of law. According to Gerd Oberleitner,

> "institutionalizing human rights also means squeezing values and ideas that were meant to empower individuals into the straitjacket of international institutional law […] the predominance of law in human rights ensures that any possible gains come at the cost of excluding other views – sociological, anthropological, religious etc. It creates a system caught in its own doctrinal border and rituals, inaccessible to the outsider and unresponsive to innovation." (Oberleitner, 2007,19)

After all, the direct effects of human rights law are vastly overshadowed by indirect effects (Brinks and Gauri 2008, 338). Other tactics such as lobbying, campaigning, advocacy and service innovation are likely to be more influential and wide ranging than litigation. Activism may be rights-based, but not legal. Article 23 may slowly lead to a cultural shift, and it is this that may be most empowering to disabled people (Foley 2012).

In conclusion, it appears to me that the symbolic impact of the CPRD may be greater, over time, than the instrumental impact, and this is particularly the case with Respect for Home and Family. As outlined in this chapter, Article 23 does imply a programme of actions with regard to both negative and positive freedoms in the area of sexual and reproductive rights, and it seems probably that where these actions are implemented, the relationship and family possibilities for disabled people will be greatly expanded. As disabled people are seen, and see themselves, as rights-bearing subjects, not the objects of pity and charity, they will also be seen as more desirable as lovers and partners, and more competent as parents. Ultimately, barrier-removal cannot stoke desire, just as legal protection will not get anyone laid. But indirectly and in the long term, the CRPD will contribute to the building of a world in which disabled people are more likely to enjoy intimacy and family life.

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