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National Human Rights Consultation
National Human Rights Consultation Secretariat
Attorney-General's Department
Central Office
Robert Garran Offices
National Circuit
BARTON ACT 2600

SUBMISSION TO THE NATIONAL HUMAN RIGHTS CONSULTATION

Thank you for the opportunity to make a submission to the National Human Rights Consultation. This submission seeks to draw the Committee's attention to the human rights issues for people with intellectual disability.

Please find attached the IDRS submission to the National Human Rights Consultation. This consists of:

1. The IDRS submission
2. The individual submissions of people with intellectual disability who were assisted by IDRS to make their submissions
3. A copy of the plain English factsheet and submission developed by IDRS for people with intellectual disability

Please note that the individual submissions ***are not to be published or publicly accessible*** because they contain sensitive and confidential information and the authors of these submissions have expressed their wish that these remain confidential. IDRS is happy for its submission to be publicly accessible without these individual submissions.

If you require any further information please contact Janene Cootes, Executive Officer, on (02) 93180144.

Yours Sincerely,

Janene Cootes

Executive Officer

IDRS SUBMISSION TO THE NATIONAL HUMAN RIGHTS CONSULTATION

Our submission integrates the views of individuals with intellectual disability about human rights which are derived from their own individual submissions to the National Human Rights Consultation, and are attached to the end of our submission.

1. Summary

In summary:

- IDRS supports a national human rights framework.
- This legal framework should include a federal Human Rights Act (HRA).
- The HRA should protect *all* human rights listed in the international human rights instruments, particularly for the purposes of people with intellectual disability, the Disability Convention
- As part of its national human rights framework, the Australian Government should sign and ratify the Optional Protocol to the Disability Convention
- The HRA should place obligations on the Commonwealth government to consider human rights in the development by Government of legislation and policy and decisions made by government officials and disability service providers t a policy and individual level
- The HRA should also provide individuals with the option of seeking relief for breaches of human rights in relation to Government decisions and the decisions of Government funded disability services
- The HRA should also enact specific human rights laws ensuring minimum standards informed by human rights in relation to institutional settings (such as prisons, immigration detention facilities, disability institutions, nursing homes and disability service group homes) and in relation to the provision of services to vulnerable groups such as people with intellectual disability

- In light of the fact that many of the government departments and legislation relevant to people with intellectual disability are at the state level, the national human rights framework should include a plan for discussions (perhaps through COAG) with Australian State and Territories with the view to the implementation of human rights legislation in each State and Territory. Moreover, the HRA should include the adoption of a clause similar to s 10 of the *Racial Discrimination Act 1975* (Cth) ('RDA') which invalidates certain state laws that are incompatible with the RDA. A provision like this in a federal HRA would ensure that people with intellectual disability are able to enjoy all of the rights afforded in the HRA.
- For people with intellectual disability, the HRA itself will not be enough to ensure the realisation of their human rights. It is also about the accessibility of these rights, their relevance to the lived experience of people with intellectual disability and that their interpretation is informed by positive understandings of intellectual disability.
- We urge that the Government, in order to ensure that the development, implementation and operation of the HRA is effective in relation to people with intellectual disability and other marginalised groups, implement comprehensive education and publicity programs about human rights, produce accessible material about human rights and enforcement procedures, and ensure access to legal advice and representation for people with intellectual disability to enforce the HRA
- Decision makers who are rationalising why their decisions in relation to people with intellectual disability meet the human rights legal requirements of the HRA *must* also explicitly state the underlying view of intellectual disability informing their interpretation of human rights in order to ensure that the interpretation of human rights is not informed by negative perceptions of intellectual disability

2. Who is the Intellectual Disability Rights Service?

The Intellectual Disability Rights Service ('IDRS') is a community legal centre that provides legal services to persons with intellectual disability throughout New South Wales. IDRS's services include the provision of telephone legal advice and legal representation in select matters. IDRS engages in policy and law reform work and community legal education with a view to advancing the rights of people with intellectual disability. IDRS also operates the Criminal Justice Support Network ('CJSN')

which supports people with intellectual disability when they come into contact with the criminal justice system, particularly at the police station and at court.

Much of our work involves promoting the human rights of persons with intellectual disability so that they can make their own life choices and live independently and with dignity, and to have equitable access to justice. In the course of our work, we utilise existing (limited) human rights protections, such as disability discrimination, criminal law procedural protections and the Disability Service Standards. The work of IDRS is thus closely aligned with human rights and, should Australia introduce new human rights legislation, this will be central to our future advocacy work.

IDRS is also involved in human rights through its community education work. We run a 'Rights Leadership' course for people with intellectual disability. This course seeks to inform course participants about their rights in relation to key areas of their lives and equip them with the skills to become self advocates and advocates within their communities. The course is co-taught by two educators, one of whom has intellectual disability.

Moreover, IDRS has had direct involvement with the drafting process of the Convention on the Rights of Persons with Disability ('the Disability Convention'). Our current Principal Solicitor, Mr Ben Fogarty, attended the Eighth Ad Hoc Committee Meeting of the (then) Draft Disability Convention in August 2006, as a representative of the National Association of Community Legal Centres. Our centre remains committed to being involved with the Disability Convention .

IDRS has engaged in various activities in relation to the National Human Rights Consultation. In recognition of the lack of accessible resources on human rights and the National Human Rights Consultation, IDRS produced a plain English factsheet about human rights and the National Human Rights Consultation and a plain English NHRC submission form. This was partially funded by the Australian Human Rights Commission. On 1 June 2009 IDRS held a Human Rights Day which was attended by people with intellectual disability. The morning involved an overview about what human rights are and brainstorming about human rights in our lives. During the afternoon session all attendees wrote individual submissions to the National Human Rights Consultation with the assistance of solicitors. The submissions inform the content of this submission. These submissions and a copy of the fact sheet that we produced are attached to the end of this submission. The submission and the factsheet are examples of how human rights can be made accessible to people with intellectual disability.

3. Preliminary considerations about human rights and persons with intellectual disability

Prior to answering the questions set by the Consultation, IDRS wishes to emphasise the importance of human rights to persons with intellectual disability. This is particularly because there is a great risk that any HRA introduced as a result of the Consultation will be ineffective in realising the rights of persons with intellectual disability.

3.1 High level of Government involvement in the lives of people with intellectual disability

Persons with intellectual disability have a high level of contact with the government through being the recipient of services and support. This is due to such factors as their low socioeconomic status and contemporary disability policy that focuses on supported community living. Their low socioeconomic status means that persons with intellectual disability may receive welfare payments and reside in public housing. Supported community living can involve living in government operated or funded institutions or housing, and receiving government operated or funded case management, psychology or therapeutic services, day programs and respite care. Human rights are one way to ensure that the decisions that Government officials and Government funded disability service providers make about people with intellectual disability and the way they treat people with intellectual disability in providing support and services is fair, respectful, non-discriminatory and enhances their independence, equality and socioeconomic status.

People with intellectual disability are disproportionately represented in the criminal justice system as offenders and in the care and protection system as parents. Significant decisions are made about individuals with intellectual disability by government officials and Courts concerning the removal of their liberties and the removal of their children from their care. In light of the seriousness of these issues, a HRA can ensure that the treatment by government officials and the Courts of persons with intellectual disability in their journey through these systems is fair and just.

It is important to note that in NSW, many of the government departments and legislation relevant to people with intellectual disability are at the state level, such as criminal law, child protection law, substituted decision making and the provision of disability services. A federal HRA will be largely ineffective in relation to these state-based areas (and hence to the lived experience of people with intellectual disability) *without* legal mechanisms to invalidate State laws and a plan to work with States and Territories to introduce human rights legislation at the State level.

3.2 Negative perceptions about intellectual disability

Government policy in relation to intellectual disability has only recently focused on people with intellectual disability living in the community and being treated equally. One should not forget the historical focus in government policy on institutionalisation, eugenics and criminalisation in relation to people with intellectual disability (or their historical predecessors – idiots, the feeble-minded, the mentally deficient, the mentally retarded). Names and policy approaches might change, but the fear and ignorance about intellectual disability still lingers and influences the actions of government officials, service providers and members of the public. The focus in human rights on non-discrimination and equality is an important mechanism to addressing the underlying negative perceptions about intellectual disability that influence how people with intellectual disability are treated generally.

However, it is important to note that confronting negative perceptions about intellectual disability is relevant not only to the realisation of the rights to non-discrimination and equality. It is also important in relation to the interpretation of human rights in the decision making processes of Government officials and disability service providers and hence the realisation of *all* human rights. Interpretation of human rights in relation to people with intellectual disability depends very much on how one perceives people with intellectual disability, including their abilities and value to the community. The interpretation of a human right will vary greatly if an individual with intellectual disability is seen as a danger or burden to society compared to if they are seen as a valuable member of society whose disability is a legitimate form of human difference. The impact of perceptions of intellectual disability are also important where there are competing claims for human rights, ie where a situation raises human rights concerns for more than one individual. These situations can arise in the context of parents with intellectual disability vis-a-vis their children and individuals with intellectual disability vis-a-vis their carers.

Thus, IDRS recommends that any HRA *must be accompanied* by the Government, service providers and society in general confronting, through discussion and awareness raising, negative perceptions about intellectual disability. Decision makers (be they government officials or court) who are rationalising why their decisions in relation to people with intellectual disability meet the human rights legislative requirements *must* also explicitly state the underlying view of intellectual disability informing their interpretation of human rights. This could equally apply to other groups subject to negative stereotypes. This should be accompanied by training and education of government officials

about intellectual disability and the employment of people with intellectual disability (both in disability liaison roles and in general positions within government).

Article 8 of the Disability Convention, concerning awareness raising, has particular relevance in relation to the points raised in this section:

1. States Parties undertake to adopt immediate, effective and appropriate measures:

(a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;

(b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;

(c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

(a) Initiating and maintaining effective public awareness campaigns designed:

(i) To nurture receptiveness to the rights of persons with disabilities;

(ii) To promote positive perceptions and greater social awareness towards persons with disabilities;

(iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

(b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;

(c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;

(d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

3.3 Accessibility of rights

It is important that the Government ensures that any human rights principles and standards that are introduced are themselves accessible (both in relation to awareness and enforcement).

The Government should ensure that people with intellectual disability have opportunities to realise their rights, including through the provision of advocacy support, legal representation and education about self advocacy. The accessibility of the enforcement of human rights should also be achieved through the HRA placing a positive obligation on Government officials and government funded disability services to consider human rights in the formulation of policies and legislation that will

affect people with intellectual disability and in the making of individual decisions about persons with intellectual disability. Such a positive obligation is important for people with intellectual disability who might not have the resources or the advocacy skills to assert their legal rights in court.

Steps should be taken to ensure that persons with intellectual disability are assisted to understand human rights. People with intellectual disability might not be aware of their human rights because information is not provided in simple, easy to understand formats. People from Indigenous or culturally and linguistically diverse communities might experience particular difficulties in accessing information. Possible methods are public media advertising campaigns, the wide dissemination of pamphlets in plain English, and the integration of human rights information into school curriculums (including mainstream schools, disability support classes, disability support units, disability support schools and TAFE).

3.4 The Disability Convention and the National Human Rights Consultation

For persons with intellectual disability, it is essential that the HRA and the national human rights framework is more broadly informed by the United Nations Convention on the Rights of Persons with Disabilities ('Disability Convention').

The Disability Convention and its Optional Protocol were adopted at the United Nations Headquarters in New York on 13 December 2006, and entered into force internationally on 3 May 2008.

Australia ratified the Disability Convention on 17 July 2008, making us one of the first Western countries to do so. By ratifying the Disability Convention, Australia has signaled its intent to join other countries around the world in a global effort to promote the equal and active participation of all people with disability in society.

The purpose of the Disability Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity. It seeks to redress the physical and social barriers, discrimination and disadvantage confronting people with disability throughout the world and to promote their full participation and recognition in civil, political, economic, social and cultural life.

The Disability Convention is particularly significant to the development of the HRA and a national human rights framework because:

- The Disability Convention does not create any new human rights but rather makes existing human rights relevant to the lived experience of people with disability. It makes general

human rights relevant and meaningful to the lived experiences of people with disability, including through imposing obligations on Governments to address the particular barriers that persons with disability encounter in realising their human rights, which in turn enhances the capacity for persons with intellectual disability to enjoy their human rights.

- The Disability Convention demonstrates the importance of involving people with intellectual disability in the development of the human rights framework. Perhaps the most outstanding feature of this international convention, which sets it apart from others, is that it was driven, drafted and debated largely by people with disability from around the globe. Over a period of about 7 years individuals with disability, met biannually at the United Nations with international Disability Peak Organisations, national Disability Peak Organisations, academics, government and non-government delegations to work on and debate the text of the Disability Convention. The slogan ‘nothing about us, without us’ was met in spirit and in reality.

Regrettably, ratification of the Disability Convention by the Australian Government does not mean that the Disability Convention and its Articles are binding law that can be argued in Australia’s courts. In fact, the Articles have no binding effect on any organisation (government or private) or private person in Australia. Conventions and treaties only have direct legal effect in Australia if, and to the extent that, our parliaments pass their own statutes to give them this effect. Nor does ratification mean that a country already fully complies with the CRPD. Ratification did require an analysis and acknowledgement that at present there are no laws in Australia that are directly inconsistent with the Disability Convention. A corollary to this is that new laws will need to be reviewed in light of the CRPD and cannot be inconsistent with it.

The legal effect of the Disability Convention (and other international conventions that Australia has ratified) is limited to two situations:

1. if the High Court has a case before it and is interpreting an Australian statute and the terms of that statute are unclear, if there is a relevant international convention on the topic, then the court can look at the articles in the international convention to help shed light on the Australian statute and remove the ambiguity, and
2. when government administrators make (administrative) decisions there is a “legitimate expectation” that they will, where relevant, take into account Australia’s obligations (contained in ratified conventions, covenants and treaties).

However, this current legal effect of the Disability Convention makes little difference to the lives of individuals with intellectual disability and the realisation of their human rights contained in the Disability Convention.

IDRS therefore submits that the HRA could be the legislative instrument that draws the Disability Convention's Articles, objectives and purposes into Australia's domestic law. A HRA could thereby properly realise the full and equal enjoyment of all human rights and fundamental freedoms by all people with disability and promote respect for the inherent dignity of people with disability. Without a HRA that embraces the Disability Convention's Articles, objectives and purposes, the Disability Convention remains aspirational and symbolic at best for Australians with intellectual disability and the HRA is likely to be ineffective for people with intellectual disability.

IDRS also submits that, as part of the national human rights framework, the Australian Government should adopt and ratify the Optional Protocol to the Disability Convention. If the Australian Government adopts the Optional Protocol, then individuals can make formal complaints (called 'communications') to the United Nations Human Rights Committee for alleged breaches of human rights under the Disability Convention. That is, if a person in Australia has exhausted all options for having their complaint heard and has been unable to obtain a remedy for the human rights breach, he or she can take their complaint to the United Nations Human Rights Committee via the Disability Convention's Optional Protocol. If the United Nations Human Rights Committee accepts the communication, they will hold a hearing and receive evidence in relation to the alleged human rights breach under the Disability Convention. They may either find the communication gives rise to a breach and make recommendations or find there is no breach and dismiss the matter. Any recommendations they make will be communicated to the Australian Government. Presently, the Australian Government is in the process of considering whether or not to become party to the Optional Protocol to the Disability Convention.

4. Which human rights should be protected and promoted?

We think that all human rights should be protected and promoted. IDRS has chosen not to provide an exhaustive list of rights to be protected and promoted. IDRS believes that the Australian Government should protect and promote all of the rights set out in the various international agreements and covenants that the Australian Government has signed and ratified. In relation to the people with intellectual disability, the most important of these international agreements is the Disability Convention.

Although we believe that *all* human rights should be protected and promoted, these rights must be relevant to the lived experiences of persons with intellectual disability. Because people with intellectual disability are still extremely excluded and marginalised within society and political processes, policy makers might not be aware of the level of and nature of disadvantage and discrimination that people with intellectual disability experience. Thus, there is a risk that benchmarks as to the realisation of human rights through a HRA might fail to consider the experiences of people with intellectual disability. Therefore, IDRS has paraphrased some of the general human rights below in order to reflect the lived experience of people with intellectual disability.:

The right to be equal

- Be treated as equal and not be discriminated against (*Convention on the Rights of Persons with Disabilities* (hereafter referred to as the 'Disability Convention') Arts 5, 12)
- Be heard and respected as a person (Disability Convention Arts 29, 30)
- Be understood and accepted for who they are (Disability Convention Arts 29, 30)
- Have a fair trial if they go to court (Disability Convention Art 13)
- Be treated with respect by (Disability Convention Arts 5, 9, 12, 13, 14)
 - o judges,
 - o police,
 - o court workers and
 - o lawyers

The right to be part of the community

- Choose where to live and be part of the community if they want (Disability Convention Arts 9, 14, 19, 29, 30)
- Go to school and get an education (Disability Convention Arts 9, 19, 24)
- Work and choose what work to do (Disability Convention Arts 16, 19, 27)
- Have a girlfriend or boyfriend (Disability Convention Arts 19, 22, 23)
- Have children, including conceiving, fostering or adopting children (Disability Convention Arts 19, 23)
- Have friends and spend time with who they want (Disability Convention Arts 19, 22)

The right to be treated well

- Be free and safe and not be treated badly (Disability Convention Arts 14, 15, 16, 17)
- Help from police, ambulance and fire services when needed (Disability Convention Art 19)
- Have a good life (Disability Convention Arts 28, 29, 30)
- Have enough food to eat (Disability Convention Art 28)
- Have a place to live (Disability Convention Arts 19, 28)
- Have good healthcare (Disability Convention Arts 25, 28)
- Government officials and service providers understand and respect people with intellectual disability (Disability Convention Arts 5, 9, 12, 13, 14, 19, 28)

The right to choose how they live their lives

- Make their own choices (Disability Convention Arts 19, 21)
- Be asked about decisions that affect them (Disability Convention Arts 19, 21)
- Have information I understand and assistance to help persons with intellectual disability make decisions (Disability Convention Arts 6, 9, 21)
- Have privacy (Disability Convention Art 22)
- Have help from services if they need (Disability Convention Arts 19, 26)
- Complain if they don't have a good service (Disability Convention Arts 13, 29)

5. Are these human rights currently protected and promoted?

Our discussion concerns human rights protections vis-a-vis people with intellectual disability in NSW as IDRS is a NSW based service for people with intellectual disability.

There is only very limited human rights protections for people with intellectual disability in NSW.

5.1 General protections***Human Rights legislation***

There is limited capacity for human rights legal protection in Commonwealth law through the *Human Rights and Equal Opportunity Act 1986* (Cth). This Act created the Human Rights and Equal

Opportunity Commission (now the Australian Human Rights Commission ('AHRC')). AHRC can investigate claims of discrimination and harassment (including on the basis of disability) and conciliate complaints under the above Commonwealth laws. However, AHRC does not have powers to make any orders (like an award of compensation or an injunction). If a matter does not conciliate, it must be pursued in the Federal Court or Federal Magistrates' Court.

AHRC, under its Act, can also investigate alleged breaches of human rights under some of the international conventions, covenants and treaties that Australia has ratified (including the ICCPR, ICESCR, CROC and ILO). However, AHRC can only investigate and make recommendations about such alleged breaches – it cannot make a finding and order compensation, like a Court or Tribunal.

In NSW, there is even more limited human rights legislative protection. The *Anti-Discrimination Act 1977* (NSW) provides scope for the investigation and conciliation of claims of discrimination and harassment, including on the basis of disability, but it does not include the broader power to investigate breaches of human rights.

Constitutional protections

There are some laws in Australia that protect human rights, but there is no overarching charter or bill of human rights, like there is in every other Western democratic country. The Commonwealth Constitution contains some 'implied rights' (to freedom of political expression and freedom of association, for example) but these are few in number and narrowly construed. These rights have little relevance to the situation of people with intellectual disability. Moreover, what remedies there are for breaches of human rights, are limited in scope and usually attained only through lengthy, expensive and exhausting Court cases. Constitutional protections are therefore an inadequate and inappropriate way of protecting the rights of people with intellectual disability.

This submission now discusses the human rights issues in some specific legal areas that are particularly relevant to persons with intellectual disability.

5.2 Disability Services

People with intellectual disability receive NSW Government and NSW Government funded disability services. These services can cover many aspects of individuals' lives such that the provision of these services has an extremely significant impact on individuals and, conversely, the service providers have a central role to play in the realisation of recipients' human rights. IDRS has repeatedly

encountered various issues with disability service provision which raise serious human rights concerns:

- People with intellectual disability can be the victims of sexual and physical abuse or neglect by disability service staff. Victims face difficulties in reporting such crimes directly to police and, when incidences are reported to disability service staff, incidences are commonly subject to ‘internal investigations’ by *the same* organisation that employs the alleged perpetrator which can commonly result in no report being made to police or no action against the alleged perpetrator and hence no protection or compensation for the victim.
- The actions of disability service providers can draw service users into the criminal justice system. Where a recipient of services displays ‘challenging behaviour’, threatens or injures staff or other service users or damages property of the service, disability support services commonly contact the police, even where this is contrary to their own stepped procedures that see contacting the police as a last resort and even where the underlying cause for the incident is systemic or environmental (rather than the individual fault of the person with intellectual disability). This can result in the service user being subject to criminal charges or AVOs.
- Disability services do not always have the experience in providing assistance to alleged offenders with intellectual disability. The limited support services for alleged offenders has ramifications for bail, sentencing and diversion applications which can in turn result in harsher penalties or restrictions of liberty for persons with intellectual disability than if services were available or if they did not have intellectual disability. Similar problems arise with accessing drug and alcohol and other mainstream support services, although problems relate more to these services not having the disability experience.
- People with intellectual disability living in disability service operated accommodation do not always have a secure place in a particular residence and can be shifted by the service provider to other residences, sometimes far away from family, social and support networks and employment, with little say in these decisions. This is particularly the case where a resident displays ‘challenging behaviour’ or is the subject of an AVO against other residents or staff.

The *Disability Services Act 1993* (NSW) (‘DSA’) governs the provision of NSW government funded disability services and articulates the rights of service recipients vis-à-vis services. The DSA articulates the rights of service recipients which service providers must apply in the provision of services including ensuring the provision of services necessary to enable persons with disabilities to

achieve their maximum potential as members of the community and achieving positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities.¹

Despite the articulation of these rights, the DSA does not actually 'create any statutorily enforceable rights for breach of the objects, principles and applications of principles'² – s 25(1) of the DSA states that '[n]othing in section 3 or Schedule 1 (nor in any application of those provisions by this Act) gives rise to, or can be taken into account in, any civil cause of action'. Rather, the DSA is more focussed on accountability of disability service providers to the State in relation to their funding.³ In its Report on *Review of the Disability Services Act 1993* (NSW), the New South Wales Law Reform Commission ('NSWLRC') noted that the 'only sanction currently available in the DSA for non-compliance is the withdrawal of funding to a service' under s 16(1).⁴ Ironically, the NSWLRC stated that such sanctions are unlikely to be made 'because such action would cause a decline in the standard of service or closure of the service [which would] significantly disrupt the lives of service users, who, given the lack of available disability services, may be unable to find alternative accommodation'.⁵

Despite the NSW Disability Services Standards, the NSW government itself continues to house hundreds of people with intellectual disability in large congregate institutional settings which breach its own standards and fail to protect the human rights of residents. Most other states of Australia have sought to close such institutions. Further, the NSW government's plan for refurbishment of these institutions, in the view of IDRS and other disability advocacy organisations, yet again fails to comply with the NSW Disability Services Standards. Such aspirational statements have failed to protect the human rights particularly of people with intellectual disability in NSW who continue to live in institutional settings some having spent their entire lives there.

Therefore, the DSA, whilst being a strong articulation of the rights of people with disabilities vis-à-vis services does not provide any cause of action to protect the rights of people with intellectual disability. Rather, it disempowers defendants as service recipients, rendering them vulnerable to

¹ *Disability Services Act 1993* (NSW) ss 3(a), 3(e); Sch 1 cl 1(b), 1(c), 2(a), 2(g).

² New South Wales Law Reform Commission, *Review of the Disability Services Act 1993* (NSW), Report No 91 (1999) [9.21].

³ See, eg, *Disability Services Act 1993* (NSW), ss 9(1), 20(a)-(f).

⁴ New South Wales Law Reform Commission, *Review of the Disability Services Act 1993* (NSW), Report No 91 (1999) [9.2].

⁵ *Ibid*, [9.3].

having to accept whatever services that they are given and to experience the negative consequences of these services.

The issues concerning disability services raises human rights issues concerning access to justice (Disability Convention Art 13), liberty of the person (Disability Convention Art 14), freedom to live in the community (including through access to housing and social services), freedom from cruel, inhumane and degrading treatment (Disability Convention Art 15 and 16).

Example from individual submission of person with intellectual disability:

“The system is inadequate to address abuse – can have complaints looked at if the service is licenced or government funded, but if it’s not, they can’t do anything about them... can’t complain about the policy of the service (to the Abuse and Neglect Hotline) The Hotline is very limited in the complaints it can deal with – they can’t do anything about service policies unless the policy breaches the standard – the onus is on the person to make a complaint and prove that there’s been a problem this can be difficult to do... (unless the service is denying you a service – and this is open to interpretation)”

5.3 Criminal Justice System

People with intellectual disability are overrepresented in the NSW criminal justice system as alleged offenders. Their overrepresentation is due to such factors as:

- Underutilisation of support persons: People with intellectual disability are entitled to a support person at police stations and at Court. The support person assists the individual with intellectual disability to understand the arrest and court process, to ensure that their rights are protected and to make them feel comfortable with the arrest and court processes. Without a support person at the police station, an individual with intellectual disability might make admissions or agree to questions asked by the police because they do not understand their rights, do not understand what is being asked or feel intimidated. They may open themselves to more charges if they respond aggressively or oppositionally to police in light of feeling intimidated, confused or discriminated against by the police’s behaviour. Unfortunately, police are currently underutilising support persons:
 - o Police have difficulty in identifying that a person has an intellectual disability.
 - o Access to a support person depends a lot on the good will of the police and the culture and practices of each Local Area Command
 - o There is a scarcity of trained support people to attend police station supports, especially out of hours and in regional areas of NSW not covered by the main CJSN regions of Sydney, Illawarra and the Hunter. Currently, most support persons are volunteers and are not paid for their time.
- Lack of disability support services (both for early intervention and in relation to bail, sentencing and diversion): IDRS has seen many instances where alleged offenders with

intellectual disability are refused bail, receive harsher sentences or are not diverted out of the criminal justice system because of a lack of suitable disability support services, notably accommodation and case management. For example, one client of CJSN who was diagnosed with intellectual disability and also had an acquired brain injury and alcohol and other drug issues was unable to be given bail because his previous violent behaviour meant that there were no services in the area willing to offer him accommodation.

- Harassment, discrimination and targeting by police
- Low socioeconomic status,

These raise human rights issues concerning equal treatment before the law (Disability Convention, Arts 5, 12), access to justice (Disability Convention, Art 13), liberty of the person (Disability Convention, Art 14) and freedom to live in the community (including through access to housing and social services) (Disability Convention, Art 19).

Example from individual submission by person with intellectual disability:

“The police came to my house and arrested me at my house. The police didn’t explain to me what was happening. I didn’t know that they were coming to arrest me. They took me to the police station and searched me and charged me. No one explained to me what was happening. I was afraid. I didn’t know what was going on. A police officer told me that she was going to break my arms and legs, and they pinched me. They never called a support person for me.”

“I have had dealing with the police before. On one occasion when they questioned me I didn’t get an opportunity to speak with my legal counsel. After then when I had to go to court, I appeared before a magistrate. I felt the magistrate dealt with me fairly but I pleaded before I had an opportunity to speak with my legal counsel or receive legal advice as my legal representative wasn’t there yet. I think I should in those situations have the opportunity to get proper legal advice before having to make such decisions.”

5.4 Capacity and Supported Decision Making

Legal capacity is an issue that potentially affects all Australians. Being assessed and regarded as not having legal capacity (or sometimes as it is called, ‘mental capacity’) to make decisions for yourself and about yourself is one of the greatest incursions on the liberty, rights and dignity of a person. The question of capacity is raised for people with a wide range of disabilities – intellectual disability, dementia, mental illness, dementia, Alzheimer’s, autism, neurological diseases (like Huntington’s

disease) and acquired brain injury. With an ageing population the question of legal capacity and how society responds to it will become even more common.

People with intellectual disability are autonomous and independent human beings. Just because a person has an intellectual disability does not mean they can't make decisions for themselves, or decide what they want to do or how they want to spend their money - even if others don't agree with them. People with intellectual disability regularly contact IDRS to say that a family member or their financial manager (like the Protective Commissioner) is refusing them money because they don't agree with how they want to spend it.

Supported decision-making is always to be preferred to substituted decision-making. The latter wrests all control from the person and should always be a last resort. Legal capacity and the ability to make financial and life decisions need to be regarded as fluid concepts that may vary from time to time and from decision to decision; not as static, unchanging and one-time-only classifications.

It is crucial that diminished legal capacity (based on cognitive impairment) is not confused with difficulties or impairment in communication. Some people have a disability that affects the way they communicate, but not how they think. With the right adjustments and support of those around the person, such a person can communicate their wishes and express themselves – for instance, using augmentive communicating devices or letter boards.

IDRS promotes the following views in respect of people with intellectual disability and decision-making:

- The wishes, opinions and choices expressed by a person are paramount
- The least intrusion and intervention possible in the decision-making of a person
- Legal capacity and the ability to make financial and life decisions need to be regarded as fluid concepts that may vary from time to time and from decision to decision; not as static, unchanging and one-time-only classifications
- It is crucial that diminished legal capacity (based on cognitive impairment) is not confused with difficulties or impairment in communication – some people have a disability that affects the way they communicate, but not how they think
- Supported decision-making before substituted decision-making – substituted decision-making as a last resort
- Working, accountable and trustworthy informal arrangements and support are preferred over formal orders made by the Guardianship Tribunal or Supreme Court

Each State and Territory also has guardianship and financial management laws (in NSW, see *Guardianship Act 1987* (NSW); *Protected Estates Act 1983* (NSW)) for people who do not have legal capacity and for whom it is in their best interests to have a guardian and/or financial manager appointed for some or all aspects of their life and financial affairs. The *Guardianship Act 1987* (NSW) is framed in the context of the principles of the best interests and least restrictive alternative. However, *Guardianship Act 1987* (NSW) and the *Protected Estates Act 1983* (NSW) arguably detract from some human rights (for example, the right to choose and autonomy Disability Convention Art 12) of a person in favour of other human rights that reflect a more paternalistic approach to people with disability (for example, the right to be free from abuse and exploitation Disability Convention Arts 15, 16). This is the case particularly in relation to the *Protected Estates Act 1983* (NSW) which is not even framed in the principle of least restrictive alternative, contrary to Article 12 of the Disability Convention .

IDRS considers that guardianship and financial management laws play an important role in protecting the interests of people with intellectual disability where their disability affects their decision-making capacity and there is no other safe, accountable and informal form of supported decision-making available. However, through their very operation, guardianship and financial management laws involve an erosion and, in some cases, entire abrogation, of the autonomy and self-determination of the persons over whom they are made. Some of the issues in relation to substituted decisionmaking are:

- Assumptions and attitudes of family, friends, Police, businesses, lawyers and others that just because a person has an intellectual disability they cannot make decisions for themselves. There is no presumption in law that a person with intellectual disability does not have legal capacity to look after their affairs. They have the right to make their own decisions and, where necessary, to be supported by others to help them make decisions about their lives. They can decide such things as who they want to have as their partner, where they want to live and what they want to do with their money, just like everyone else. Unfortunately this legal presumption does not always coincide with societal attitudes to capacity. Often well-meaning people in the life of a person with intellectual disability employ paternalism to decide what they think the person needs, desires and what they believe is in the person's best interests.
- There is a lack of services to help development decision-making capacity. This is particularly the case in relation to financial management.
- An unwillingness and failure by people to make reasonable adjustments (as is already an obligation under Australia's disability discrimination laws and the Convention on the Rights

of Persons With Disabilities) to accommodate the disability of a person and thereby wrongly 'deem' them "incapable" – this is particularly so where a person, because of their disability, communicates in an alternative mode.

- Where an organisation, like the Office of the Protective Commissioner or Office of the Public Guardian, is the financial manager or guardian, use of 'client service teams' with the effect that there is no particular person responsible for any particular client.
- Slow (to no) responses from the guardian or financial manager to requests and enquiries from the person.
- Slow decision-making or failure to make decisions by guardians and financial managers (for example, paying bills for the person).
- An unwillingness by guardians and financial managers to spend the time needed to understand the needs, changing circumstances and idiosyncrasies of the people whose lives and finances they manage.
- Inadequate expertise, resources and assistance for people with intellectual disability to oppose or challenge an application for guardianship or financial management at the time it is made and at any subsequent review.

It is hoped that the HRA can reinforce and promote Article 12 of the Disability Convention and the following principles in respect of the decision-making capacity of people with intellectual disability (and other cognitive impairments):

- The wishes, opinions and choices expressed by a person are paramount
- The least intrusion and intervention possible in the decision-making of a person
- Legal capacity and the ability to make financial and life decisions need to be regarded as fluid concepts that may vary from time to time and from decision to decision; not as static, unchanging and one-time-only classifications
- It is crucial that diminished legal capacity (based on cognitive impairment) is not confused with difficulties or impairment in communication – some people have a disability that affects the way they communicate, but not how they think
- Supported decision-making before substituted decision-making – substituted decision-making as a last resort
- Working, accountable and trustworthy informal arrangements and support are to be preferred over formal orders made by the Guardianship Tribunal or Supreme Court

5.5 Care and Protection

Parents with intellectual disability are overrepresented in the NSW child care and protection system. The human rights of parents with intellectual disability are not sufficiently protected and promoted. This section of the submission will focus on care and protection proceedings in the NSW Children’s Court and the consequent effect upon the rights of parents.

In NSW, the Care and Protection legislation, the *Children and Young Persons (Care and Protection) Act 1998* NSW (the Act), rarely mentions the rights of parents.⁶ In fact, some see the rights of parents and the least intrusive intervention principle as being in conflict with the safety, welfare and wellbeing of the child.⁷ The Act has therefore recently been amended by the *Children Legislation Amendment (Wood Inquiry Recommendations) Act 2009* (NSW). Chapter 2 of the Act, which sets out the objects and principles, will now be significantly altered by the new 2009 Act. The reference to “the rights of the parents” in s.8(a) and s.9(a) of the Act, although only ever secondary rights and never rights at law⁸, will now be entirely removed.⁹ These amendments are contrary to Article 3(2) of the *UN Convention on the Rights of the Child* (‘CROC’) which specifically states that the rights and duties of parents are to be taken into account in child protection proceedings. The rights of parents should not be seen as subordinate to, and in conflict with, the rights of the child, but should instead be seen as central to the safety, welfare and well-being of a child.

Other amendments to the Act which will specifically impact on the rights of parents with intellectual disability are the insertion of the words “capacity” at s.8(a)¹⁰ and “incapable of consenting” at s.151(3)(b) of the Act.¹¹ These amendments create a further window for discriminatory assumptions, prejudices and stereotypes.

Specific human rights issues for parents with intellectual disability are:

- Freedom from discrimination: Discrimination against persons with intellectual disability should be eliminated in all matters relating to marriage, family, parenthood and relationships. (Disability Convention, Art 23.1) No child should be separated from parents

⁶ *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.98(1)(a) & s.163

⁷ *Report of the Special Commission of Inquiry into Child Protection Services in New South Wales*, The Hon James Wood AO QC, November 2008 pp417-423.

⁸ *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.7

⁹ *Children Legislation Amendment (Wood Inquiry Recommendations) Act 2009* (NSW) Sch 1.2[3]

¹⁰ *Children Legislation Amendment (Wood Inquiry Recommendations) Act 2009* (NSW) Sch 1.2[2]

¹¹ *Children Legislation Amendment (Wood Inquiry Recommendations) Act 2009* (NSW) Sch 1.3[8]

on the basis of a parent's intellectual disability. (Disability Convention, Art 23.4) The means necessary to enable parents with intellectual disability to exercise their rights should always be provided so as to ensure discrimination is eliminated. (Disability Convention, Art 23.1(b)) However, people's assumptions, prejudices and stereotypes influence mandatory reports and the response to reports.

Example:

In a care and protection matter that an IDRS solicitor was involved in, a DoCS caseworker who had found out from a report on the DoCS Helpline that the parents have intellectual disability, failed to speak to the parents about the exact nature of their disability and how it may have impacted on their parenting capacity. The caseworker failed then to find out diagnostic information about the disability, how the parents felt their disability affected them and the level of supports they had available to them and/or needed. This in turn meant that the caseworker was unable to provide appropriate support services to the parent which in turn impacted on DoCS' views about the placement of the child.

- The right to retain fertility and to practice their sexuality: All persons with intellectual disability, including children, should have the right to retain their fertility and to practice their sexuality on an equal basis with others. (Disability Convention, Art 23.1(c)) This is discussed in more detail below in the section on sterilisation.
- The right to found a family: All adults with intellectual disability should have the right to found a family on the basis of free and full consent . (Disability Convention, Art 23.1(a)) All persons with intellectual disability should have the right to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education. (Disability Convention, Art 23.1(b))
- The right to protection of and respect for home and family: The family is the natural and fundamental group unit of society and should be entitled to the widest possible protection by society and the State. (CROC preamble, ICCPR, Art 23.1, ICESCR Art 10.1)
- The right to an adequate standard of living: All persons with intellectual disability should have the right to an adequate standard of living for themselves and their family, including adequate food, clothing, housing and the continuous improvement of living conditions. (Disability Convention, Art 28)
- The right to assistance: Australia should render appropriate assistance to parents with intellectual disability in the performance of their child-rearing responsibilities, including the provision of material assistance and support programmes. (CROC, Arts 18(2), 24(2)(e)-(f) &

27(3), Disability Convention, Art 23(2)) The failure of DoCS to properly inform themselves of the extent and nature of a parent's intellectual disability means that DoCS may therefore fail to provide appropriate supports or referrals for the parent, and instead commence care proceedings removing the child. Support and assistance play a legitimate role in enhancing the parenting capacity of parents with intellectual disability, and without intellectual disability. Section 21 of the Act allows a parent to seek assistance from the Director-General to obtain services to enable the child to remain in, or return to, the care of his or her family. Section 22 of the Act, however, does not force the Director-General to provide that assistance. One of the options open to the Director-General is to instead commence proceedings to remove the child.

Example:

IDRS has heard first hand of an account where a mother with an intellectual disability in a domestic violence situation approached DoCS for assistance. DoCS did not provide her with that assistance, but rather commenced care proceedings and removed the children from the care of the mother.

- The right to privacy and reputation: No one should be subjected to arbitrary or unlawful interference with his or her privacy, family or home, nor to unlawful attacks on his or her honour and reputation. (Disability Convention, Art 22)
- The right to care for their children: All parents with intellectual disability should have the right to know and care for their children. (CROC, Art 7.1) Parents should have the primary responsibility (with assistance from the State) for the upbringing and development of the child. (CROC, Arts 18.1, 18.2)
- The right to maintain relationships with their children: Where a child has been removed from the care of a parent with intellectual disability, the parent should have the right to maintain personal relations and direct contact with the child on a regular basis. (CROC, Art 9.3) Once children have been removed, contact with their parents is often in a foreign environment. In addition, contact is often supervised by persons unfamiliar to parents and unskilled and inexperienced in working with people with intellectual disability. This makes contact stressful for parents with intellectual disability, and may impact on their engagement with the child. In addition, contact times are often inflexible and contact points are often logistically difficult for parents to attend. In terms of the legislation, s86 of the Act (Contact Orders) is amended by Schedule 1.2 [24] of the new *Children Legislation Amendment (Wood Inquiry Recommendations) Act 2009* which states that the Children's

Court may make an order stipulating minimum contact frequency and duration only where it is an interim order, or where restoration is a realistic possibility. This will severely impact on a parent's contact and their right to maintain relationships with their child when contact can no longer be ordered by the Court, and is left to the discretion of an overloaded DoCS. It is difficult to see how either DoCS's contact practices or the amendments to the Act relating to contact are in the child's best interests.

Example:

A different caseworker in the same matter as in the example above who stated she had no experience or training in communicating with persons with intellectual disability failed to adequately explain why certain suggestions were made about parenting conduct at contact visits. The parents then become frustrated as they did not understand why they had to follow certain instructions and they failed to follow some of the caseworker's advice. This then impacted on the caseworker's views about their parenting capacity, the appropriateness of restoration, the likely success of the parents working with DoCS and the frequency or terms of contact following placement.

Example

A client of IDRS (a mother with an intellectual disability) must travel on a public bus with her daughter (who also has an intellectual disability) in order for them both to visit her son who is in care in a boys' home. The public bus ride is 38 kilometres each way. Contact is once per fortnight. The boys' home is responsible for ringing the mother two days before the contact to confirm the contact, however the boys' home often forgets to ring the mother.

- The right of parents to provide direction, general guidance and religious guidance: All parents with intellectual disability should have the right to provide appropriate direction and guidance to their child in relation to the rights of the child, including freedom of thought, conscience and religion. (CROC, Arts 5, 14) Section 79 of the Act allows the Court, amongst other possibilities, to order that parental responsibility be shared by the parents and the Minister. For parents with intellectual disability sharing responsibility with the Minister, it is questionable how fair and real the sharing of parental responsibility can be. A parent with intellectual disability may find it difficult to communicate their opinions about their child and their child's best interests, especially in a stressful meeting at the premises of DoCS. Further, the parent may not have an advocate present. Administrative pressures on DoCS

often dictate the extent of involvement of the parent, therefore diminishing the parent's rights. Alternatively, parental responsibility may be held solely by the Minister, in which case the parent may be completely denied their right to select the education and religious upbringing of their child.

- The right of parents to educate their children: There should be respect for the liberty of parents to decide upon their child's school, and the moral and religious education their child receives. (ICESCR, Art 13(3)) The education of a child should be directed to the development of respect for the child's parents, cultural identity, language and values. (CROC, Art 29.1(c))
- The right of appearance: All parents with intellectual disability should have a right of appearance in Care and Protection matters.¹² Guardians ad litem should be used with greater caution.¹³ Currently under the Act each person having parental responsibility for the child has the right to appear in Children's Court proceedings.¹⁴ For parents with intellectual disability this right can be affected, sometimes negatively, by the appointment of a guardian ad litem.¹⁵ Once a guardian ad litem is appointed, the parent loses their direct voice. Their lawyer must then act on the instructions of the appointed guardian. There are no clear procedures or high thresholds for the appointment of a guardian ad litem and there are no statutory provisions for the removal of the guardian ad litem. Furthermore, s.101(2) of the Act inappropriately equates intellectual disability with incapacity to instruct.

Example:

A mother with intellectual disability only recently made contact with IDRS. Approximately 6 years ago proceedings in the Children's Court concluded and care orders were made by consent. The IDRS solicitor was informed by DoCS that a guardian ad litem was appointed in the proceedings, but only in the end stages, ie when orders by the consent of the guardian ad litem were finally made. The IDRS solicitor was told by DoCS that it was and is best practice to have a guardian ad litem appointed whenever a parent has an intellectual disability. IDRS are unsure who the lawyer representing the mother 6 years ago was. The IDRS solicitor has no difficulties obtaining instructions from the mother.

¹² *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.98(1)(a)

¹³ *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.101

¹⁴ *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.98(1)(a)

¹⁵ *Children and Young Persons (Care and Protection) Act 1998* (NSW) s.98(2)&(2A), s.101

Examples from individual submissions by persons with intellectual disability:

“I went into an institution when I was 3 ½ years old because my family couldn’t look after me. I came out of the institution when I was 17 ½ years old. In those days families were told to put infants with intellectual disabilities into institutions and forget about them.”

“I want to talk about the worst thing that happened to me. This was when my younger daughter K... was nearly taken away from me and my husband by DOCS. K was only a new born baby. She was in hospital for weight loss related to a reflux-like condition...Dr T thought we weren’t feeding her properly and her weight loss was our fault. He didn’t believe it was reflux. He thought we were neglecting her...I felt like we were being made to feel that we were bad parents. He [Dr T] blamed our intellectual disability because of K’s weight loss. Dr T called DOCS...DOCS took us to court to try to remove the girls... we didn’t have a chance to speak to lawyers.

... From my story I want the government to learn that doctors should diagnose children first and make referrals to proper medical specialists rather than making reports to DOCS and blaming parents with disability.”

“[DOCS] served an affidavit on us in relation to a court application by DOCS to remove our children...The affidavit was about 2cm thick or so. They asked if I understood the affidavit. I didn’t say anything because DOCS have lots of power and I didn’t want to argue. On this occasion when DOCS gave me the affidavit, they threw it at me because [they] said that I wouldn’t understand it... all my problems with DOCS were worse because I didn’t have an advocate or anyone else to support me. ...

I want DOCS to change and get training to understand intellectual disability, including parents and/or children with intellectual disability.”

5.6 Sterilisation

IDRS is deeply concerned about the Australian Government’s approach to sterilisation of children with intellectual disability. This approach is outlined in the Australian Government Fourth Report under the Convention on the Rights of the Child dated May 2008 (see paras 131-134).

IDRS’s position on sterilisation is that:

- sterilisation is a fundamental breach of an individual’s human rights, such as the right to bodily integrity and the right to bear children
- sterilisation is a question for adulthood, not childhood

- sterilisation is a procedure with profound, adverse and life-long psychological and physical effects
- any law or policy on sterilisation should apply to all children, not exclusively to children with disability
- people with intellectual disability can be parents and should not be sterilised in order to prevent them from reproducing
- the sexual exploitation of children with intellectual disability should not be addressed through sterilisation of potential victims as this only prevents the physical manifestation of sexual exploitation (ie pregnancy), rather than putting an end to the sexual abuse itself
- any difficulties that parents and carers encounter in providing an adequate standard of care to children with intellectual disability (particularly those purported difficulties related to menstruation) should be addressed by the government through greater allocation of resources and support to parents and carers rather than through sterilisation
- children with intellectual disability should be provided with education and emotional support concerning menstruation, puberty, reproduction and pregnancy in order to alleviate any fears, distress or confusion they might experience concerning these events
- the abilities of children with intellectual disability are not fixed, but evolve over time depending on the level of support and education they are provided with, such that a definitive conclusion concerning their future abilities to be parents, to manage menstruation or to engage in sexual conduct, which forms the basis of a rationale to sterilise a child, cannot be made based on their present level of abilities

Historically, sterilisation has been used for eugenic means in order to prevent the reproduction of certain groups within society on the basis of fears about these groups which are informed by stereotypes and myths, with the ultimate aim of eliminating that group from society. This is typically epitomised by the United States Supreme Court decision of *Buck v Bell* (1927) 274 US 200 and in the actions of the Nazis in World War II. Arguably, in today's society it is considered inappropriate to use sterilisation for such means. Instead, sterilisation is rationalised in positive terms such as improving an individual's 'quality of life' and being in the individual's 'best interests' – ie it is focused on enhancing the lives of children with intellectual disability rather than obliterating them as a group. Despite this, IDRS submits that these new rationales for sterilisation are ultimately motivated by similar stereotypes and fears that formed the basis of sterilisation in the eugenics era such as people with intellectual disability being incapable of parenting. Moreover, the Australian government only

considers its laws and policies on sterilisation should apply to children with disability (see the recent Standing Committee of Attorneys General draft model bill titled 'Children with Intellectual Disabilities (Regulation of Sterilisation) Bill), which reflects the eugenic idea of sterilisation targeted at a particular group in society.

IDRS submits that sterilisation should only be permissible when it is pursuant to a Court or Tribunal order and that order is made following satisfaction of a narrow legal test – where that procedure is necessary to save the child's life or to prevent serious damage to the child's health (this test currently operates in the NSW Guardianship Tribunal: see *Guardianship Act 1987* (NSW) Pt 5; *Children and Young Persons (Care and Protection) Act 1998* (NSW) s 175). This test is not limited in its application to people with disability but rather anyone who is incapable of consenting: see *Guardianship Act 1987* (NSW) s 33. Any legal test should be capable of applying to any child who cannot themselves consent to the procedure rather than being specifically applicable by its terms only to children with disability. IDRS urges all Australian Governments to work together to develop universal legislation which prohibits sterilisation of any child unless there is a serious threat to health or life.

IDRS opposes the broader 'best interests' legal test that currently operates where sterilisation is authorised pursuant to the Family Court's welfare jurisdiction (s 67ZC of the *Family Law Act 1975* (Cth)). The 'best interests' test is vague. What is considered to be in the 'best interests' of a child with an intellectual disability is vulnerable to influence by stereotypes about people with disability and the interests of parents and carers. Although there are clear legal tests for ordering sterilisation (eg s 67ZC of the *Family Law Act 1975* (Cth)), IDRS is concerned about the contents of these tests. As stated above, it is IDRS's view that sterilisation should only happen where there is a serious threat to a child's health or life. IDRS opposes the Family Court's 'best interests' test on the basis that it is vague and broad and can enable the sterilisation of children with intellectual disability for reasons such as stereotyped views about the sexuality and parenting skills of children with disability or the burden of care they present to their parents. The application of the best interests test for such reasons is contrary to the right to non-discrimination contained in CROC. IDRS urges the Australian government to introduce uniform legislation prohibiting sterilisation except where the narrow test of serious threat to health or life is satisfied. The test under the *Guardianship Act* is very narrow - the Guardianship Tribunal has jurisdiction to consent to sterilisation as a 'special medical procedure' on a person who is incapable of consenting where that procedure is necessary to save the patient's life or to prevent serious damage to the patient's health: *Guardianship Act 1987* (NSW), s 45. This narrow test would not be met in all circumstances where other alternatives have proved unsuitable.

The sterilisation of a child in circumstances other than where there is a serious threat to the health or life of that child effectively denies the child present and future enjoyment of her or his human rights. In particular, it is contrary to the human rights contained in CROC.

It is extremely concerning that Australia does not consider sterilisation to be a breach of CROC, as illustrated by its comments in the Draft Report concerning the permissibility of sterilisation for children with disability.

Sterilisation is relevant to the following provisions of CROC:

- Article 2.1 concerning States ensuring the rights in CROC without discrimination against children with disability such that laws and policies permitting sterilisation should apply to *all* children on an equal basis rather than exclusively applying to children with disability
- Article 6.2 concerning States ensuring the development of the child because sterilisation other than in circumstances other than where there is a serious threat to the health or life prevents the sexual and social development of a child
- Article 19.1 concerning States protecting children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation because sterilisation should other than in circumstances other than where there is a serious threat to the health or life involves an invasive procedure resulting in the permanent removal of the ability to reproduce and lifelong psychological effects
- Article 23.1 concerning States ensuring that children with disability enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community because sterilisation other than in circumstances other than where there is a serious threat to the health or life prevents the sexual and social development of a child
- Articles 23.2 and 23.3 concerning the provision of additional assistance to parents of children with disability in a manner conducive to each child's achieving the fullest possible social integration and individual development because sterilisation is typically rationalised on the basis that it alleviates the 'burden of caring' for a menstruating girl with an intellectual disability, rather than the solution being for the government to provide additional support to parents and carers

In its 2006 General Comment No 9 on the Rights of Children with Disabilities ('General Comment') the Committee on the Rights of the Child ('Committee'), noted the importance of addressing discrimination against children with disability:

‘the explicit mention of disability as a prohibited ground for discrimination in article 2 is unique and can be explained by the fact that children with disabilities belong to one of the most vulnerable groups of children. ... Social stigma, fears, overprotection, negative attitudes, misbeliefs and prevailing prejudices against children with disabilities remain strong in many communities and lead to the marginalization and alienation of children with disabilities.

Girls with disabilities are often even more vulnerable to discrimination due to gender discrimination. In this context, States parties are requested to pay particular attention to girls with disabilities by taking the necessary measures, and when needed extra measures, in order to ensure that they are well protected, have access to all services and are fully included in society.’ (para 8, para 10)

Specifically in relation to sterilisation, the Committee expressed its deep concern about

‘the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States parties to prohibit by law the forced sterilisation of children on grounds of disability.’ (para 60)

Specifically in relation to Australia, the Committee in considering Australia’s report under Article 44 of the CRC (Fortieth Session), encouraged Australia to: ‘prohibit the sterilization of children, with or without disabilities, and promote and implement other measures of prevention of unwanted pregnancies, e.g. injection of contraceptives, when appropriate.’ (p 10)

Sterilisation is also contrary to the following rights contained in the Convention on the Rights of Persons with Disabilities (CRPD):

- Art 23.1 concerning States taking measures to eliminate discrimination against persons with disability in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure the rights of people with disability to retain their fertility on an equal basis with others, found a family and have access to age-appropriate information, reproductive and family planning education
- Art 23.2 concerning States rendering appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities
- Art 17 concerning the physical and mental integrity of persons with disability

- Art 3 concerning non-discrimination and respect for the evolving capacities of children with disability

It should also be noted that the Committee on Economic, Social and Cultural Rights in its 1994 General Comment No 5 on Persons with Disabilities referred to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly on 20 December 1993, stating that ‘persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood’. The Committee emphasised that ‘both the sterilisation of, and the performance of an abortion on, a woman with disabilities without her prior consent are serious violations of article 10 (2) [of the International Covenant on Economic, Social and Cultural Rights]’.

It is truly questionable why the Australian government is so persistent about the permissibility of the practice of sterilising children with intellectual disability in the face of international human rights law to the contrary.

5.7 The Importance of socioeconomic rights

It is vital that the HRA includes social, economic and cultural rights (and civil and political rights), rather than only civil and political rights. The lived experience of people with intellectual disability demonstrates the importance of social, economic and cultural rights. This is particularly because of such factors as their experience of poverty, homelessness, unemployment, poor access to health care and use of government and government funded services. Enjoyment of social, economic and cultural rights will be central to the enjoyment of civil and political rights.

In particular the Australian Government should focus on the right of people with intellectual disability to equal opportunities to:

- (a) Maintain an adequate standard of living (Disability Convention, Art 28): People with intellectual disability should have an equal right to maintain an adequate standard of living as other members of the community. In particular it is important that disability pension payments are maintained at an adequate level given that many people with intellectual disability struggle to find paid employment to supplement their income. This means that disability pension payments should be sufficient for people with intellectual disability to pay food, housing, clothing, medical, transport, social and recreational activities and other essential expenses. Our experience suggests that the current level of disability pension

payments may not always be sufficient for people with intellectual disability to maintain an adequate standard of living.

Examples from individual submission of person with intellectual disability:

“every individual should have the right to health care. Health care should be affordable.... doctors need to be educated against dismissing health conditions as ‘part of your disability’... better dental health care should be made available so that people are not waiting for months and years – rather, people should be able to get to see a dentist within a few days or hours if they are in pain...”

“Housing – should be accessible and affordable – department of housing rent hikes should be stopped and should not go up every time the pension goes up – people should also get support if they need it in their house as well... people should be able to get the size of house that they want and not just be thrown into a bedsitter.... everyone should have housing...”

“In 1998 when I worked in a mainstream job I was treated unfairly and as a piece of dirt. They were mocking me and subjecting me to indecent exposure...this effected me psychologically to such an extent that I ended up in hospital. There was no support for me at work. There was no support for me in the group home that I was living in at the time.”

- (b) Make independent social and economic decisions (Disability Convention, Art 12): We recognise that substituted decision-making by guardians appointed through guardianship and financial management orders may be necessary where people with intellectual disability do not have the cognitive capacity to make their own social and economic decisions. However we also note from experience that such guardianship and financial management orders can significantly compromise the right of people with intellectual disability to make independent social and economic decisions. As such we are often asked to advise people with intellectual disability seeking to have their guardianship and financial management orders revoked or appealed.

We should emphasise again that substituted decision making will under certain circumstances be necessary. However we also believe that people with intellectual disability should be provided with adequate legal representation and resources to ensure that guardianship and financial management orders are only made where they actually do not have the cognitive capacity to make the relevant decisions. They should also be given adequate legal representation and resources to appeal these orders where appropriate. The government could also take steps to provide education and training to private lawyers to provide such services.

- (c) Purchase goods and services with equal protection of their rights as consumers: People with intellectual disability should have the right to purchase goods and services with equal protection of their rights as consumers as other members of the community. Among other things they should be entitled to purchase goods and services at their market prices and fair terms and conditions. It also means that the suppliers of those goods and services should take reasonable steps to ensure that people with intellectual disability have an adequate understanding of the terms and conditions of the proposed purchase of goods and services.

In our view the Australian Government should regularly review its trade practices legislations to ensure that the consumer rights of people with intellectual disability are sufficiently protected. It should also provide suppliers of goods and services with education and training on how to serve customers with intellectual disability. Such education and training programs could focus for example on how to identify people with intellectual disability and the responsibility of suppliers and their employees to ensure they have adequately understood the terms and conditions of the proposed purchase of goods and services.

- (d) Engage in social and economic activities with equal protection of their right to privacy and confidentiality of personal information (Disability Convention, Arts 29, 30): People with intellectual disability should have the right to participate in social and economic activities with equal protection of their rights to privacy as other members of the community. In particular we should protect the confidentiality of their personal information such as medical history and criminal records. This may for example require the relevant government agency, private sector organisation or individual to adequately explain to people with intellectual disability why their personal confidential information is collected and how that information will be used. It may also require the information collecting entity to not disclose certain types of personal confidential information (including criminal records) of people with intellectual disability unless the entity has received the express consent of the relevant person with intellectual disability or it is required under the law to do so.

In our view the Australian Government should regularly review existing privacy legislations to ensure that people with intellectual disability are provided with equal protection of the right of privacy and confidentiality of personal information. This is as our experience suggests that people with intellectual disability are particularly vulnerable to breaches of privacy and confidentiality of personal confidential information. Very often they are unable to appreciate the risks associated with the disclosure of their personal confidential information.

Example from individual submission of person with intellectual disability:

“people should have access to a choice of jobs – not just what your employment service wants to do... I should not be given the option of going to a business service as a first (or only) option... people should be able to do the job of their choice and have support to do that job... people should get financial assistance to get ready for the job and to get to it...”

- (e) Receive education and training (Disability Convention, Art 24): People with intellectual disability should have equal rights to education and training as other members of the community. Education and training can have a very positive impact on the lives of people with intellectual disability. Mainstream TAFE courses should be accessible to people with intellectual disability through provision of student support where needed. These courses provide people with intellectual disability with the opportunity to access mainstream employment. Teaching individuals life skills (particularly if they have lived in institutional environments) such as cooking skills can help people with intellectual disability live independently within the community. Communication skills can help people with intellectual disability to better interact with other members of the community, reduce the possibility of conflict with others and advocate for their rights. Literacy and basic technical skills can enhance their chances of finding paid employment. In these ways education and training can effectively enhance the quality of life for people with intellectual disability.

In our view the Australian Government should regularly review its education legislations (including the provisions of the disability discrimination legislations which affect the rights to education and training) to ensure that people with intellectual disability are provided equal rights to education and training as other members of the community. It should also work with various state governments to ensure that there are educational and training programs adequately tailored for people with intellectual disability. It should also ensure that education and training opportunities are equally available to people with intellectual disability regardless of their circumstances. The opportunities should for example be equally available to those living in rural areas, from non-English speaking backgrounds, or Aboriginal backgrounds.

Example from individual submission of person with intellectual disability:

“TAFE advisors suggest that you start off in a specialist class rather than a mainstream class – and then they often don’t move you over to a mainstream class saying that they don’t have enough staff to support you – and you don’t have a choice... this is not good... and then only some classes will run and only if TAFE has enough people to run the class – and people will end up doing a course that has nothing to do with the job they want to do in the end... TAFE needs to put more into providing adequate support for people to do courses that they want to do and in the mainstream if that is what they want to do”

- (f) Equal access to government services: People with intellectual disability should have the right to equal access to government services as other members of the community. Government services provided through hospitals, public transport, legal aid and other public sector organisations often play a key role in the lives of people with intellectual disability. Many of them become heavily reliant on government services given they do not have the financial resources to obtain alternative private sector services. The Australian Government should work with state governments to ensure that equal access to government services is provided to people with intellectual disability. Among other things specifically tailored written resources in Easy English would assist people with intellectual disability to understand the availability of government services. Education and training for the employees of government services organizations may help them recognize people with intellectual disability and provide assistance as appropriate.

6. How Could Australia Best Protect and Promote Human Rights?

IDRS supports a legislative protection of human rights in the form of a human rights Act. IDRS wishes to draw the Committee’s attention to features that the national human rights legal framework should have in order to benefit people with intellectual disability:

- The national human rights legal framework should include a federal Human Rights Act (HRA)
- The HRA should protect *all* human rights listed in the international human rights instruments, particularly for the purposes of people with intellectual disability, the Disability Convention

- As part of its national human rights framework, the Australian Government should sign and ratify the Optional Protocol to the Disability Convention
- The HRA should place obligations on the Commonwealth government to consider human rights in the development by Government of legislation and policy and decisions made by government officials and disability service providers at a policy and individual level
- The HRA should also provide individuals with the option of seeking relief for breaches of human rights in relation to Government decisions and the decisions of Government funded disability services
- The HRA should also enact specific human rights laws ensuring minimum standards informed by human rights in relation to institutional settings (such as prisons, immigration detention facilities, disability institutions, nursing homes and disability service group homes) and in relation to the provision of services to vulnerable groups such as people with intellectual disability
- In light of the fact that many of the government departments and legislation relevant to people with intellectual disability are at the state level, the national human rights framework should include a plan for discussions (perhaps through COAG) with Australian State and Territories with the view to the implementation of human rights legislation in each State and Territory. Moreover, the HRA should include the adoption of a clause similar to s 10 of the *Racial Discrimination Act 1975* (Cth) ('RDA') which invalidates certain state laws that are incompatible with the RDA. A provision like this in a federal HRA would ensure that people with intellectual disability are able to enjoy all of the rights afforded in the HRA.
- For people with intellectual disability, the HRA itself will not be enough to ensure the realisation of their human rights. It is also about the accessibility of these rights, their relevance to the lived experience of people with intellectual disability and that their interpretation is informed by positive understandings of intellectual disability.
- We urge that the Government, in order to ensure that the development, implementation and operation of the HRA is effective in relation to people with intellectual disability and

other marginalised groups, implement comprehensive education and publicity programs about human rights, produce accessible material about human rights and enforcement procedures, and ensure access to legal advice and representation for people with intellectual disability to enforce the HRA

Examples from individual submission of person with intellectual disability:

“I wasn’t aware that people have human rights to be treated fairly at work and at court ...”

“Before the Intellectual Disability Rights Service told me about human rights I didn’t know what they were.”

“When I was living in the institution my human rights were ignored. I felt like I was treated badly by people who know their rights. We did not know our rights and weren’t told our rights – I learnt this for myself later in life”

“Have advertisements on the television, such as “violence against a person with disability is not right” (similar to domestic violence ads about women)”

“[The Government] could put something on TV, put pamphlets or flyers out. TV is for free which means lots of people will see the ads.”

“A comprehensive DVD which has information for people making discrimination complaints. DVD is good because you can watch it at your own pace.”

“The Australian Government should have a proper website. Laws should be taught at schools and everyone should have to learn basic laws. I only learnt about “safety” from the police while I was at school.”

“[The Government] should advertise rights more.

The Government departments should tell me about my rights.

People in the community should be aware of and tell me about my rights.”

- Decision makers who are rationalising why their decisions in relation to people with intellectual disability meet the human rights legislative requirements *must* also explicitly state the underlying view of intellectual disability informing their interpretation of human rights in order to ensure that the interpretation of human rights is not informed by negative perceptions of intellectual disability

7. Conclusion

For people with intellectual disability, the HRA itself will not be enough to ensure the realisation of their human rights. It is also about the accessibility of these rights, their relevance to the lived

experience of people with intellectual disability and that their interpretation is informed by positive understandings of intellectual disability.