To investigate supported decision making practices, capacity building strategies and other alternatives to guardianship.

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Signed Dianne Chartres    Dated 20 March 2012
2010 Churchill Fellowship - To investigate supported decision making practices, capacity building strategies and alternatives to guardianship

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1 Introduction and Executive Summary

The Fellowship enabled me to travel abroad to study the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and in particular, Article 12 (in full at Appendix One). This article promotes equal recognition before the law and access to the support required for decision making - an important breakthrough in advancing self-determination and equality of rights for people with disabilities. It creates a requirement that no person will have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support – and for this decision to be respected by others. Parties to the UN CRPD have an obligation to provide this support and appropriate safeguards to ensure that:

- legal capacity is not deprived,
- support is provided to make decisions and to exercise and develop legal capacity,
- the decisions made (including saying no) are respected, and that
- abuse by third parties and supporters is prevented.

The UN Secretariat identified the concept of ‘supported decision making’ as innovative practice and my fellowship enabled me to explore how this was being applied in British Columbia, Canada and in England, United Kingdom. I was also interested in the response to Article 12 by countries with less developed (or more onerous) guardianship regimes and different cultural and human rights contexts. Might the existence of modern guardianship frameworks hinder further progress towards UN CRPD goals? Might there be lessons to learn from countries with less developed or different systems? To consider this question and other capacity building strategies, I also travelled to India, Czech Republic and Hungary. Throughout my study I was privileged to meet with thought leaders on this topic, many of whom were instrumental in the design of the UN CRPD and are continuing to be involved in its implementation and monitoring.

One of these is Professor Gerard Quinn and I was fortunate to be able to spend time with him and his associates at the Centre for Disability Law and Policy, University of New Galway - where I gained greater insight on this topic and the work of the Centre. Quinn (in his writings) has suggested that while the philosophical and legal base for Article 12 is well debated (and established) the necessary practice, statutory regimes and safeguards are as yet, largely undetermined.

My observations overseas will assist policy and practice generally and specifically, a research trial of supported decision making being conducted by South Australia’s Office of the Public Advocate (OPA). As a co-principal researcher for this trial, my fellowship has generated much interest in our local efforts. An important outcome will be ongoing connections with the talented people I met overseas – people who are committed to meeting the challenges of the
UN CRPD, Article 12 and achieving real benefits and progress for people with disabilities - no matter what the starting point.

I wish to acknowledge the support in my endeavours from South Australia’s Public Advocate, Dr John Brayley and Professor Richard Bruggemann, Disability and Community Inclusion, Flinders University, both strong advocates for people with a disability. Also the Julia Farr M S McLeod Benevolent Fund, which made South Australia’s research trial possible and Cher Nicholson, SDM Project Coordinator, OPA. Cher’s insight into empowerment and thoughtful articulation of her experiences, dilemmas and the barriers encountered in trying to put in place the practice of ‘SDM’, as well as her views on what might make a difference, have been invaluable.

I am grateful to Michael Bach and Tim Stainton for not only meeting with me, but for a ‘once in a lifetime’ invitation to attend two think tanks on Article 12 that were held in Vancouver in late April and early May 2011. There I met and heard from people from around the world about their activities and thinking on how best to implement Article 12 of the UN CRPD.

I am particularly grateful to Amita Dhanda, Professor and Head, School of Disability Studies, National Academy of Legal Studies and Research (NALSAR), Hyderabad who I first met at the above events. Her wisdom and commitment has greatly influenced my thinking. She was also invaluable in helping me to connect with relevant organisations and people in India.

To all the people and organisations that generously gave their time and assisted me to coordinate my study tour – I thank you – for making it insightful and successful. My perspective has been enriched, even changed, as a consequence of my Fellowship.

I would like to express my gratitude to the Winston Churchill Memorial Trust. I am both indebted and honoured with the distinction of being a Churchill Fellow and look forward to making a continuing contribution to the Australian community, disability policy and the lives of people living with a disability, no matter where they live.
Executive Summary

In 2011 I travelled abroad to Canada, United Kingdom, Eastern Europe and India to study the implementation of Article 12 - Equality before the Law - UN CRPD. England and Canada have been at the forefront of alternatives to guardianship and supports for decision making. Australia has highly regarded guardianship practices. Might its modern systems hinder further progress? What might we learn from countries with less modern systems?

Highlights

• Meeting many people involved in developing Representation Agreements in Vancouver, BC.
• The generous time, discourse and hospitality provided to me by Michael Bach.
• An invite to attend two international symposiums in Vancouver, British Columbia, Canada.
• A frank and insightful discussion with Kate Fulton, Kellie Woodley and Di Barnes (Newcastle) and similarly with Hilary Brown, (Kent) on disability, safeguards and reforms in England.
• Time and discourse at the Centre for Disability Law and Policy, University of New Galway, Ireland.
• Discussions with Gabor Gombas (Budapest) on psycho-social disability, advocacy & Article 12.
• Meeting the young volunteer supporters in an SDM project in India (New Delhi).
• The interest in our SDM pilot in South Australia and invites to present on it in India, Canada and Ireland.
• Being privy to Amita Dhanda’s (India) insight and personal reflections on disability and the UN CRPD.

Recommendations

UN CRPD’s human development and rights approach needs to be echoed in all policies, practices and legislature. Enabling legislation should provide for assistance, supports, safeguards and accommodation for people with disability to self-determine and control their affairs. Any intervention should be the last resort & decision specific. Systemic and integrated reforms across a range of policy arenas - including monitoring of policy consistency with this goal and a stronger, or, re-oriented rights and legal capacity focus for tribunals and statutory offices.

Investment in the development of a spectrum of supports that will assist and augment decision making as well as in policies and in programs that will build inclusion and social capital and sustain and build natural relationships.

Engaging families and people with disabilities in dialogue on Article 12 and in the planning and projects for developing appropriate supports and safeguarding regimes is a necessary capacity building strategy.

Supported decision making (SDM) practice should not become ‘professionalised’; however, clear guidance is required on the issues, approach, support and context for both people with disabilities and their supporters.

Inclusion with social capital is the foremost safeguard for people with disabilities, but they still need to be protected while included. This is best provided through access to universal safeguards at all levels of intervention.

Capacity building, also a strong primary safeguard, should include rights education programs for people with disability and trial projects involving them, their families and the community. Trials that cater for younger people with disabilities and people with mental health issues, dementia or severe disabilities are also needed.

Guidance and tools for SDM and access to mediation, peer support, advocacy and independent support for making life and personal plans will be necessary for the successful implementation of supported decision making.

Consideration of legal capacity rights need to be extended to financial administration arrangements, informed consent, mental health laws and the defence of mental incompetence (impairment) in the criminal law.

Dissemination of my findings will be to the SDM Pilot Control Group in South Australia, Julia Farr Association, papers for conferences, journals and academic forums and references in consulting assignments. Presentations have already been given to officials and institutions abroad. I am currently networking and engaging in collaborative studies and research abroad, which is another highlight of my Fellowship.

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Program

The program encompassed two separate periods of travel and a personal extension to attend two international seminars in Vancouver on the topic of my Fellowship.

13 April - 3 May 2011

13-15 April Vancouver, British Columbia, Canada
Tim Stainton – Director, School of Social Work/Center for Inclusion & Citizenship University of BC
Jay Chalke and Kimberly Azyan - Public Guardian and Trustee (PG&T), BC
Robert Gordon – Simon Fraser University, BC, Canada
Joanne Taylor - NIDUS Personal Planning Resource Centre, Vancouver, BC

18-19 April North York, Ontario, Canada
Michael Bach - Canadian Association for Community Living
Gordon Keele - Canadian Association for Community living
Orville Endicote - Legal Counsel, Community Living Ontario
Julie and staff -, Disability Services, Government of Ontario

20-21 April Manchester and Newcastle, United Kingdom
Julie Stansfield – CEO, In Control, Manchester
Kate Fulton - Senior Consultant, Paradigm, Newcastle
Kellie Woodley - Skills for People and Independent Mental Capacity Advocate (IMCA), Newcastle
Di Barnes - Board of Trustees, Skills for People, Newcastle

26-28 April London, United Kingdom
Hilary Brown - Senior Consultant, Salomon’s Campus Canterbury Christ Church University, Tunbridge Wells
Raquel Gonzalez – Coordinator, Inclusion International, Docklands, London
Judge Lush - Senior Judge, Court of Protection (as above)
Martin Stephens - Kings College, London

Arising from contacts in Canada while arranging and undertaking my Fellowship, I was invited to attend two sessions at the University of British Columbia, Vancouver, Canada.

29 April- 3 May University of British Columbia, Vancouver, BC, Canada
31 August – 3 October (Fellowship Resumed)

Attending the two sessions at the University of British Columbia (above) and breaking my Fellowship travel into two stages was done at my own expense. The Fellowship resumed in September, 2011

2 – 9 September Dublin and Galway, Republic of Ireland

Christine Linehan - Director National Institute for Intellectual Disability, Dublin

Fiona Keogh - Research and Information Manager, Genio, Dublin

Mary van Lieshout – National Disability Authority, Dublin

Professor Gerard Quinn - Director, Centre for Disability Law & Policy NUI Galway

Charles Mahony - PRTLI Ph.D. Fellow Centre for Disability Law & Policy NUI Galway

Mary Keys - School of Law, College of Business, Public Policy and Law, NUI Galway

Deidre Carroll – Inclusion Ireland, Dublin

Patricia Rickard-Clarke – Commissioner, Law Reform Commission, Dublin

10 – 16 September Budapest, Hungary and Prague Czech Republic

Gabor Gombas – Independent Expert – Article 12 and UN CRPD, Budapest, Hungary

Sandor Gurbai - Project Manager, Legal Capacity, Mental Disability Advocacy Centre (MDAC), Hungary

JUDr. Dana Kořínková - QUIP – Společnost pro změnu, Prague, Czech Republic

Milena Johnova – QUIP – Prague, Czech Republic

19 – 1 October Hyderabad, Bangalore and New Delhi, India

Amita Dhanda and students – School of Disability Studies NALSAR, Hyderabad, India

Meera Ramchard - Association for the Mentally Challenged (AMC), Bangalore, India

Srinivasa Murthy and parents - AMC, Bangalore Murthy, Bangalore, India

J P Gadkari - Director, Projects & Development, PARIVAAR, Bangalore, India

Smt Poonam Natarajan - National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities, New Delhi, India

Shardamani Iyer – Project Coordinator, SDM Demonstration project, Delhi

Student Volunteer Supporters – SDM Project, Delhi
Background

Australia ratified the UN CRPD in July 2008 and assented to become a party to the Optional Protocol in August 2009. This commits states, agencies and service providers to make all reasonable accommodations in their dealings with people with disabilities so they can exercise their legal capacity. As many people are unaware of the background and conventions, these are summarised below.

FIGURE 1: TIMELINE AND PROCESS FOR UN CRPD DEVELOPMENT

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>The drafting of UN CRPD commenced when the government of Mexico sponsored a General Assembly (GA) resolution calling for an Ad Hoc Committee (AHC) to be formed to this effect.</td>
</tr>
<tr>
<td>July 2002</td>
<td>Over a period of just 4 years and at 8 meetings of the AHC, the international community discussed, debated and drafted the UN CRPD.</td>
</tr>
<tr>
<td>December 2006</td>
<td>- The AHC created a Working Group to pull together a draft text and considered amendments by delegates in its sessions.</td>
</tr>
<tr>
<td>August 2006</td>
<td>- The main body of the Convention and its Optional Protocol were finalised and December submitted to a Technical Drafting Committee. One of their responsibilities was to ensure it had the same meaning in the 6 official languages of the UN.</td>
</tr>
<tr>
<td>13 December 2006</td>
<td>- UN CRPD and its Optional Protocol were unanimously adopted by the GA, making it “the most rapidly negotiated human rights treaty in the history of international law” (UN Secretary General, Kofi Annan). Another first was that people with disabilities, the key stakeholders, were at the centre of negotiations and drafting of the UN CRPD.</td>
</tr>
<tr>
<td>30 March 2007</td>
<td>- Once adopted, a Convention is opened for signature and on this first day 81 countries signed the UN CRPD – but this did not commit them to implement it. Ratification through a legal process, usually by the Parliament of the signatory country, is required. After 20 countries have done so, a Convention comes into force and the signatories become a State Party to a Convention. Once in force, State Parties must implement it.</td>
</tr>
</tbody>
</table>

Australia, along with many other countries, made some reservations/declarations on ratification of the UN CRPD and its Optional Protocol, including (that)–

‘……..Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards………..’

People with Disability Australia (PWD), through and with the National Association of Community Legal Centres (NACLC) argued that guardianship (and substituted decision making) is important for the realisation and protection of human rights for some people with disabilities. They did
however note, the ‘enormous potential for abuse and neglect within guardianship arrangements’ and that in other parts of the world, there are guardianship regimes that are ‘unnecessarily plenary and permanent in nature, invest responsibility for decision making in persons with conflict of interest, are not subject to appropriate review, and are associated with institutionalisation and abandonment, among many other problems’. They recommended modernisation of guardianship systems and guardianship standards, including the individual tailoring of substitute decision making so that it applies for only the time, issue at hand and as an absolutely necessity and stringent safeguards against abuse (7th Session Ad Hoc Committee). This position was in contrast to that of the Intellectual Disability Caucus (IDC) who opposed the continuation of guardianship regimes (5th Session Ad Hoc Committee) and of the Intellectual Disability Alliance (IDA) whose principles for implementation (at Appendix Two) promote more radical reform.

Australia’s guardianship system is modern and overall, already and conceptually, a good one. The emphasis is on maintaining informal arrangements, pursuing the least restrictive option and appointing substitute decision makers only as a last resort. There has been considerable investment in the development and quality of guardianship services, but the downside of this is that non–statutory decision making support services are less developed, if at all. Consequently, persons who might otherwise be able to make a decision themselves (with communication assistance or personal support) may have a guardian appointed because of an absence of this support. Similarly, family conflict, lack of supportive family or friends and circumstances may be as much a trigger for guardianship as a person’s capacity. Many care or treatment providers prefer to deal with a legal guardian rather than with someone whose capacity is in question.

Recently, most states in Australia report a peak in demand for guardianship services, a trend running counter to the objectives of the UN CRPD and Article 12. The challenge created by UN CRPD to re-think guardianship and decision making rights is therefore both timely and important.

The social model of disability

The purpose of the UN CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities and to promote respect for their inherent dignity.

The social model of disability underpins the UN CRPD. This suggests that an adult or child is only ‘disabled’ or ‘impaired’ to the extent that their environment, circumstances and responses to their needs, lead to loss or limitation of opportunities to take part in the life of the community on the same basis as others. This includes interventions such as guardianship and trusteeship. It demands a new way of thinking about vulnerability and risk, and our responses to these issues.

Not all vulnerable people have a disability and not all people with disability are vulnerable.
Research and practice tells us that within all population groups, some are more vulnerable than others and require specific policy and responses to help keep them safe. For people with disability, for example, exposure to risks often arises from service settings and dependencies, inadequate service provision and poor quality and/or discriminatory practices. Too often, they experience further victimisation by an intervention or order being placed on them (restrictions, loss of rights and freedoms) or by the very systems designed to protect the wider population (poor access to justice, redress or recovery support).

Consistent with the social model of disability, Hilary Brown (2003)? suggests that people with a disability ‘are only vulnerable to the extent that their rights are not upheld or insofar as they are excluded from, or unable to gain access to, mainstream mechanisms for protection and redress’.

**Reasonable Accommodations**

The UN CRPD defines reasonable accommodation as

‘(the) necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.’

The Convention requires agencies and service providers to make all reasonable accommodations in their dealings with people with disabilities so they can exercise their legal capacity. The implementation of Article 12 has many policy implications, including, when should guardianship be invoked and how guardianship services should be delivered (if at all), what efforts must be made to avoid or limit the loss of legal rights even when traditional test (s) of capacity can not be fully met, how to meet the expectation it creates that people will be given assistance to make their own decisions and only appointing a substitute decision maker when this is not possible?

The assumption of legal capacity, the obligation on signatories to the UN CRPD to provide decision making supports and the principle of ‘reasonable accommodation’ are concepts that should redefine how people think about capacity. The provision of decision making support can nurture self-determination and choice, decision making skills and life experience. The development of policies and community attitudes that are accepting of a more liberal and extended approach to capacity can create and grow the opportunities for people with disability to participate as citizens, consumers and service users in their own right.
Developing Supported Decision Making Practices

Article 12 of UN CRPD promotes equal recognition before the law and decision making support for people with disabilities.

The principles of personal autonomy and self-determination are not debated; it is accepted that it is better for a person to make a decision for his or her self, rather than have a decision made for them. Where there is debate, is how far the guardianship system in Australia needs to move to comply with Article 12? Compliance suggests a yes or no response. Is a better question, what more can be done to progress towards and achieve the aspirations and outcomes envisaged by and for people with disability, which the UN CRPD confers as basic human rights?

For Michael Bach, an international expert, redefining capacity and reforming substitute decision making are important foundations for meeting the requirements of Article 12. In Australia’s case, where guardianship systems have for a long time sought to maintain informal arrangements and pursue the least restrictive option, one view might be that we already comply. However, the tenet of supported decision making (SDM) is to neither rely on guardianship nor nebulous informal arrangements and to provide clarity about what is offered in the way of support.

SDM has its origins in the disability field and related movements, particularly in Canada. In this regard, the work of an NGO in British Columbia NIDUS (formerly Representational Agreement Resource Centre) was highlighted on the UN Secretariat Enable website and in a handbook prepared for parliamentarians, as best practice.

A recent Australian definition of supported decision making is that

‘Supported decision-making (SDM) is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control. Responsibility, including legal responsibility, is another essential aspect that needs to be considered.’

In South Australia, the Office of the Public Advocate (OPA) is investigating whether supported decision making can be an effective alternative to substitute decision making with wider potential benefits. Can supported decision making, facilitate, provide a tool and safeguard for ensuring people with a disability make their own plans and choices in life wherever possible?

And beyond this, build community inclusion?

The SDM Research Trial assists people to develop relationships with supporters, provides education to third parties about supported decision making and helps establish supported decision making plans. An independent evaluation will assess whether SDM serves as an effective alternative to substitute decision making and beyond this, its wider possible benefits?
The SA Trial is being piloted in the context of current legislation. While it is consistent with the aims and purpose of South Australia’s *Guardianship and Administration Act 1993*¹³, in practice the tendency is to jump straight to guardianship because there is, as yet, no formalised approach to SDM or practice guidelines. (This is similar to the experience of other Australian states and many overseas countries). The trial aims to develop both policy and practice options, including appropriate safeguards. A recent radio interview with people with disabilities involved in this trial can be found at [http://www.abc.net.au/am/content/2011/s3398274.htm](http://www.abc.net.au/am/content/2011/s3398274.htm)

Other states in Australia are closely watching our trial and some are looking at initiating their own trials, such as that proposed in NSW. This will take a different approach to SA, locating the project in state government within the policy setting jurisdiction for people with disability sector, which is responsible for providing supports for people to achieve their citizenship potential. It will also have a focus on person-centered approaches and self-directed funding arrangements. In 2012 collaboration between the Ageing, Disability and Home Care, the Public Guardian and the NSW Trustee and Guardian will progress two stages: a development phase to develop new tools, resources and frameworks, followed by a pilot phase to test out the tools with a small group of people with disability. Unlike the SA trial, it will also include financial decision making.

**Safeguards**

Retaining rights should not mean that either people themselves or the community will be at a greater risk.

A broad (or holistic) approach to safeguarding will encourage involvement before any decision making abuses occur and will seek to influence attitudes across the whole community to achieve this end. Conversely a narrow approach will see a focus on intervention after harm has been done, and in the long term, greater damage to the individual and cost to the community and government.

I commenced the study tour with the premise that:-

- the decisions likely to work best for a person, will be the ones they make for themselves rather than those made for them;

- substitute decision making of some form will probably still be required in some for people living with severe or profound impairment;

- it is critical that any safeguards to protect SDM from abuses, must also maintain its integrity as an alternative to substitute decision making;

- SDM is likely to need a legislative framework and will require some changes to existing statutory guardianship frameworks operating in Australia. (This need has already been
signalled by the Victorian Law Reform’s preliminary findings on its review of guardianship law in that State); and

- to a large extent the UN CRPD’s requirement on others to make reasonable accommodations will be fundamental to its adoption and success; this too, will need monitoring and review at the individual and systems levels.

Having worked in disability, mental health, advocacy and guardianship I appreciated that the impact of Article 12 would be far reaching. It has the ability to change the lives of people living with disability through respecting (and supporting) their capacity for self-determination and right to personal autonomy. Conceivably, a whole gambit of policies, practices, attitudes and behaviours across the wider community would need to change, and change dramatically.

The focus of my Fellowship however was guardianship regimes and practices; on how these might be improved in line with SDM and the safeguards needed to adequately protect vulnerable adults within such frameworks.
Report

The findings arising from my fellowship are reported under the headings of preamble, observations in each initial destination (Canada and UK), reflection, followed by further inquiry and observations in subsequent study destinations (Ireland, Hungary, Prague and India) and conclusions and recommendations. It would be impossible to describe in this report all of my experiences and lessons, instead the aim is to stimulate discussion in some key areas relevant to the Australian context.

Preamble - some initial reflections

The UN CRPD covers many diverse countries. At the date of my Fellowship, there were 148 signatories to the Convention and 90 signatories to the Optional Protocol – translating to 100 ratifications of the Convention and 61 of the Protocol.

The guardianship and human rights regimes that exist in these countries vary considerably, as do the potential for abuses or over-use of state interventions. When looking at international experience and reform it is vital to take this into account - and as well – each country’s unique history, demography, culture and systems of social support and government. None the less, the exposure arising from doing so is invaluable and an important stimulus for reflecting on the Australian experience.

A surprising but positive finding was how international agents or agencies including disabled person’s organisations (DPOs) and their networks are working together, respecting their differences, to achieve a platform on which to guide the implementation of UN CRPD and Article 12 and supporting each other’s efforts to bring about change in their countries of origin.

In many ways Australia as a whole is disconnected from this momentum and focus. A momentum strengthened by the European Union (EU) which has made a landmark ratification of the UN CRPD as a regional body), the European Court of Human Rights and well established DPOs with membership of Inclusion International, their affiliates and other coalitions. The various initiatives that are occurring at the state level in Australia have a lot to offer. More international engagement would benefit both Australia and other countries. I also found that by comparison with Australia, in the countries I visited there was more grassroots and as well academic attention given to the topic of equality before the law. (A finding which has brought home to me the merits and foresight of the Churchill Memorial Trust Fellowships). A downside of this was a degree of frustration about the postulating and potential ‘paralysis’ that could accompany such discourse. Accordingly, there was great interest shown in SA’s SDM pilot because it was practical and was effectively action research that would inform policy and future legislative options.
An objective of my study tour was not only to hear about the approach of others, but also to share my Australian experiences and the insight I was gaining along the Fellowship journey. In addition to my study program, I presented at the University of Galway and to some 60 students at NALSAR, Hyderabad India. The opportunity to do this with discussion was an invaluable component of my Fellowship. It helped me to test out and consolidate my insights and observations.

I found that each country that I visited is endeavoring to move forward from different starting points and bring the UN CRPD and Article 12 to life within their own circumstances and those of their citizens living with a disability.

Observations
Several states in Canada have legislative provisions for supported decision making or for appointing representatives through written agreements. The purpose of my visit to Canada was twofold; firstly to understand how the British Columbia representative agreements work and secondly, to discuss with Michael Bach his views on the topic.

In British Columbia, Canada supported decision making is a legislated option. The Representation Agreement Act 1996 provides detail on this approach and its operation.

This enables a system of agreements between a trusted friend and relative, who supports the person with their decision making and at times or in some situations makes a substitute decision on their behalf. They can also decide in advance on issues. The Act embraces a presumption of capacity for persons with intellectual disabilities and mental illness, and enables them to enter this ‘contract’ even though normally, under contract law, they would have been deemed to lack capacity to do so. They can amend or revoke these at any time. An additional safeguard is the appointment of a monitor. This is mostly a voluntary appointment, except where stipulated as essential in some circumstances prescribed by the Act.

The provision of representation agreements circumvents court involvement. The organisation NIDUS grew from the original efforts for legislative reform and today it provides support and assistance to people with disabilities (including dementia), their families and supporters to make their agreements. These agreements can be registered for a fee with NIDUS. The Act never anticipated, nor legislated for a registration process, so this process is purely voluntary.

While the legislative provisions, agreements and the NIDUS service are promoted by the British Columbia Public Guardian and Trustee, the take up is relatively small (though an agreement can be made without the involvement of NIDUS). I was advised that legal professionals are
cautious about their use. The agreements compete with arrangements put in place by private (for profit) trustee companies, traditionally dominated by accountants and legal professionals. The Act’s development was closely aligned to a movement to community living, largely parent led and the representation agreements, similarly grew out of the need for parents to have security about the plans for their son and daughters future, especially when they are no longer able to, or not around to care for them – and also in these new living arrangements.

This in part relates to the fact that advance directives cannot be made by someone who lacks capacity, and so was meeting this gap rather than an overuse of guardianship. The high cost of making an application to the court for guardianship is a huge disincentive for most. (I was told amounts ranging from C$5000 to C$8000)

While people in institutions might come under the jurisdiction of the Public Guardian and Trustee, generally a person with a developmental disability would not be under their guardianship or trusteeship.

This is because they are unlikely to have property and assets and a low likelihood of high incomes. The situation that we have in Australia, where people with developmental disabilities on pensions, income support or disability adjusted rates of pay are often under financial administration, just does not occur. Of significance, help to manage budgets, make regular expense payments and to pay service agencies for support received, is provided by the benefit provider (e.g. social services).

As seniors are more likely to have assets, they are more likely to come under trusteeship and/or guardianship. It appears that seniors (as at May 2011) experience a higher level of scrutiny and safeguarding interventions than do people with developmental disabilities. On the one hand, this is the least restrictive option but on the other, this might expose people with developmental disabilities to a risk of exploitation.

One person thought that this reflects a tension probably found throughout the world; seniors are more concerned about protection and people with disabilities more about liberty. In both cases, however, the role of the state and potential loss of autonomy and self-determination, are significant human rights issues.

In the future more people with developmental disabilities may have assets as a result of a federal Registered Disability Savings Plan (RDSP). This enables families or the person with a disability to attract grants, matched co-contributions from the government and tax deferred interest earnings. In effect it provides a vehicle for a person with disability to save and accumulate liquid assets which they can realise after turning 59 years. At that time it is
converted to an allocated pension that does not affect other disability benefits. A lump sum to assist with disability related expenses can also be withdrawn. An irony was that many people with disabilities, depending on the laws and provisos of their state/province had problems in accessing the scheme – because of their incapacity. Work has been done to either get around this (for example Micro Boards19, including for individual funding for services) and advocacy for policy amendments. Through this scheme, in 20 years’ time there will be people with disability with assets. Will the circumstances of families who contributed have changed, was the primary motivation taxation and/or grant benefits, might they see the entitlement as a reward for years of care and more likely, could these people be preyed upon and financially exploited due to their assets and perceived vulnerability?

The degree to which there is a wider market for private or not for profit guardian and trustee services, as in the United States (US) and their efficacy is not clear. (I noted adverse Canadian press about one of these organisations operating in Oregon, US). Certainly there was a view that if so, greater regulation was required and a combined approach (social and legal), with the benefit that this would serve to “temper” approaches. It also begs the question of the role of the state in such interventions and systems. I was told that in British Columbia, if a person has an advance directive and a representation agreement, the latter will override the former.

In Canada (as in the UK) the concept of a network of people providing support, known as circles of friends or support is far more developed than in Australia, and in some states, guardianship arrangements incorporate concepts of tutorship or advisory councils. Micro Boards are another concept involving a network of supporters.

There are some very different drivers of reform in Canada, past and in the future, and a very different starting point for supported decision making than the current Australian experience.

There were mixed views on the need for a resource agency such as NIDUS. Some saw it as a much needed support and resource for people with disability and their families; others thought that service providers should be instrumental in promoting and advocating for agreements to be in place. This was because the latter would help take up and to universalise the approach.

Many people expressed disappointment in the fact that our South Australian pilot had excluded people with a diagnosis of dementia and mental illness (for very good reasons). This was not a criticism. It was because in their opinion supported decision making can and has worked with people with these diagnoses, it is inconsistent with a non – diagnostic or labelling approach to capacity and because it is a contentious area worldwide. Our SA project and its accompanying evaluation may have shed some light on some of the operational dilemmas and informed both debate and practice.
In Ontario, Canada I met with Michael Bach and several of his associates. Michael is active in trying to reform guardianship laws and practice in Ontario and has given input into the crafting of the UN CRPD. He is the Executive Vice-President of the Canadian Association for Community Living (CACL), a national advocacy organisation with a focus on advancing the human rights and inclusion of people with intellectual disabilities and their families. CACL is a federation of over 400 local community living associations and 13 provincial/territorial associations. While his work predominantly reflects the Canadian experience he has also contributed to projects in Latin America, Europe and India.

Personhood is a key tenet of Michael’s advocacy and writings on legal capacity for people with disabilities. He (amongst many others) suggests that philosophy and law tells us that the meeting of three basic criteria is needed to enable a person to be equally recognised and respected as a person:-

a) decision making capacity;
b) a recognized intention or will; and/or
c) personal identity and history - seen and known by others as the same person over time.

This is why the concept of supported decision making is so important; it can help an individual to meet these criteria, and illuminate this to others, so that they can be treated as a full person in their own right and before the law.

The decision making capacity criterion needs to be considered with much caution; many people with disabilities will have been denied the life experiences and opportunities that develop these skills. There is also a tendency to raise the bar on decision making for people with disabilities; judgements come into play about the correctness, the wisdom, the rationality, the risk and effect of a decision that others never encounter.

Michael explains decision making capability as a dynamic process. There is a relationship between decision making abilities, decision making supports, the accommodations made by others and the decision making status afforded them. Understanding empowerment in this context is important.

Empowerment means self-determination. The UN CRPD promotes self-determination as a human right; the practice of supported decision making makes this right a reality rather than ideology. Self-determination also underpins the thinking and practice of individualised funding. But what does self-determination mean?
The perspective of Michael Bach is summarised in the following table (Figure 2). This is adapted from a paper he presented in July 2000 at the first International Conference on Self-determination and Individualized Funding.20, 21

**FIGURE 2 - LINKING SELF-DETERMINATION, FUNDING AND OUTCOMES**

<table>
<thead>
<tr>
<th>APPROACH &amp; Definition</th>
<th>Individualised Funding &amp; Planning Support</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1 CHOICE:</strong> Self-determination is defined simply as having choices.</td>
<td>Any initiatives can easily meet this test - at least on paper - of having more choices.</td>
<td>Status and power does not necessarily change. No change in relationship.</td>
</tr>
<tr>
<td><strong>2 CONSUMER:</strong> Self-determination is equated with individualized funding</td>
<td>Funding is allocated to consumers to purchase services - and by definition - they then have self-determination.</td>
<td>Evaluations show that people can obtain the cash, but not self-determination. There is still no vision or direction for one’s life and no power to move towards it.</td>
</tr>
<tr>
<td><strong>3 SKILLS:</strong> Self-determination is seen as a set of skills to make decisions</td>
<td>People who are self-determining are only those who meet the tests of intelligence and rationality required for making independent decisions and directing supports.</td>
<td>Many people with intellectual &amp; other disabilities are excluded from self-determining by this approach. In Canada people who cannot meet the self-management test might be ineligible for individual funding.</td>
</tr>
<tr>
<td><strong>4 STATUS &amp; RECOGNITION:</strong> Self-determination is respected; they have a new decision making status - regardless of skill - and a new kind of recognition from others about a person with a disability.</td>
<td>Funding &amp; planning processes need to force others to change - then look back at an individual in a new light. This recognises personhood, legal rights, authentic self, with a history and future, a personal biography, with hopes, deserving of a personal vision and life plan - a person with capacity.</td>
<td>Real power and control is transferred through the mechanisms of individualized funding and planning support. Planning and decision-making processes foster and deepen personal relationships with family, friends and support networks.</td>
</tr>
</tbody>
</table>

A **status and recognition** approach is the ideal, sits comfortably with supported decision making and is important to the context of Australia’s impending funding and allocation reforms.

Stainton (2005)22 identifies three key elements for rights based social policy and as requisites for individual funding approaches. These are;-

- ‘**support for people to articulate their claims**’
- **support for people to identify, obtain and manage supports necessary to articulate their claims, and**
- **providing (for) control over their resources**.’
In Australia, the current funding and support system is built predominately around services (or lack of these) and often the regulation, policy, practice intended to support people with disabilities reflect a deficit view of them. This diminishes not only the empowerment of persons with a disability but also community capacity, (‘people helping people’) by focussing on services and the problems, difficulties, incapacities and crises of persons with a disability. A culture of risk aversion or well-meaning paternalism and an environment of inadequate resources compound this problem. Providers, families and relatives have to present the person with a disability in the ‘worst case’ in order to attract resources and services. Consequently, their gifts, talents, capacities and contributions are rarely seen or lauded - and even more rarely, funded or supported to further develop and enjoy. Any reform to funding, as being considered in Australia through a National Disability Insurance Scheme (NDIS), needs to take account of supported decision making and a status and recognition approach to disability.

This will be a challenge: Over recent years in South Australia, and I suspect other states, assessment for and provision of funding has tended to be based on personal care or attendant care needs (i.e. the hours of support needed for this care). Eligibility and assessment for a new insurance/funding scheme needs to move beyond this if it is to do justice to the UN CRPD and its promise of a paradigm shift for people with disabilities – involved in its development, it reflects their life experiences and a new way of how they want others to think about disability.

In fact, amongst people living with disability, I noted a move back to and a preference for the terminology of ‘disabled people’, reflecting that it is social constructs, barriers in thinking and the environment and a lack of accommodation by others, that disables them.

The task is to ensure funding meets individual needs for support; but these supports must be defined in relation to a person’s vision/direction and their plan for getting there, rather than allocated on a categorical, impairment-based approach that assesses only functional needs. The latter objectifies people ‘through the judging gaze of others’, ‘consumerism’ and ignores their personhood.

In regard to guardianship and decision making:-

- A **status approach** – assumes a person lacks legal capacity because of their ‘label’, for example, intellectually disabled. Guardianship laws can strip them of their legal capacity and allow a third party to make substituted decisions. In this approach one either has full legal capacity or is deemed to universally to lack capacity.

- An **outcome approach** – focuses on the effect of a decision or a series of past decisions. If these are considered to be bad, unwise or risky, a person loses the right to make their own
decisions. It is subject to ‘judgements’ and usually ignores how people generally make decisions (and mistakes) and so sets the bar higher for people with disabilities.

- A **functional approach** - considers capacity on the basis of a specific issue and its circumstances. It presumes a person has capacity unless proven otherwise and considers whether, if with support (and further experience) they would have (or acquire) the capacity to make their own decisions.

In May 2011 when I met with Michael Bach, he was advocating for a reform of guardianship in Ontario \(^{24}\), which almost mirrored the initial thinking and conceptual framework put forward by SA’s Office of the Public Advocate. (This is attached at Appendix Three)

In his proposed schema for Ontario, people will move between decision making statuses as supports, accommodations and abilities grow and evolve. Thus he envisages a continuum of supports related to different and evolving decision making statuses ranging from facilitated, supported through to independent decision making. The diagram below, which depicts this schema and the brief outline of possible institutional arrangements are drawn from a paper entitled ‘A New Paradigm for Protecting Autonomy and the Right to Legal Capacity’, prepared for the Law Commission of Ontario by Michael Bach and Lana Kerzner, October 2010. \(^{25}\)

FIGURE 3: MAXIMISING LEGAL CAPACITY
At the time of my visit the proposition was for an institutional framework comprising 8 key components:-

1. A legislated framework for legal capacity and decision making supports
2. Legislated duties and liability, including protection, of representatives and facilitators
3. Monitors (modelled after that created in the BC Representation Agreement Act)
4. A community based resource centre, including a registration system
5. A Legal Capacity and Support Office with powers to investigate adverse effects and to act as monitor or facilitator of last resort. It would also have the role of arranging supports as needed in situations of risk of adverse effects and where such supports would enhance a person’s ability to make and/or act on their decisions
6. An administrative tribunal with an exclusive focus on decision making and powers to appoint supporters, facilitators and monitors where needed and the ability to receive and approve applications from people wishing to act as supporters. It will provide an alternative to the courts for remedial action
7. Access to legal counsel for matters before the tribunal or in seeking action from the tribunal
8. An independent formal advocate with roles of advice in relation to decision-making status, information on legal and administrative processes where capacity is an issue, support to any individual involved in a proceeding such as explaining the consequences of any orders or outcomes and helping individuals where neglect or abuse by a representative or facilitator is at issue.

Like elsewhere, the fact that SA had taken a project and practical approach to investigating the merits and practice of supported decision making was welcomed. Consequently, I was asked to present on our project to the Department responsible for Developmental Disabilities in Ontario. The application of SDM for people with severe and profound disabilities was a topic of much interest and debate.

In Ontario there was a clear view that a resource agency (like NIDUS) was an essential component of any reform towards a supported decision making or representative agreement framework.
The United Kingdom has experienced similar issues as those confronting South Australia - including high demand, public dissatisfaction with the work of the Public Trust Office, concerns about the effectiveness of guardianship and related safeguarding services and a Parliamentary Inquiry into their Trustee services. In response, and over a significant period of time (nearly a decade), the UK has implemented structural, service and legal reform to protect the rights of persons with disabilities and improve services to the public.

As a result, new mental capacity laws came into force in England and Wales. The Mental Capacity Act 2005 (MCA) was assented in Parliament in April 2005 accompanied by an implementation plan that allowed for nearly 3 years of preparation before its proclamation in October 2007. The MCA introduced Lasting Powers of Attorney for health, welfare and financial affairs and new systems and structures for their implementation. (e.g. a new Court of Protection, Office of the Public Guardian, Independent Mental Capacity Advocates, greater accountabilities and supervision for financial, health and welfare deputies and changes to the remit and roles of the Public Trustee and Official Solicitor.)

Mental Capacity Act 2005

The MCA promotes positive attitudes to ageing, mental impairment and to personal autonomy: Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person’s age, appearance, or any condition or aspect of a person’s behaviour which might lead others to make unjustified assumptions about capacity. It sets out an assumption of capacity and an obligation to take all practicable steps to help the person take his or her own decision. The MCA enshrines in law the right of individuals to make decisions themselves, with assistance if need be, unless they do not have capacity. It sets out the best practice approach to determining capacity including that assessment should be specific to the decision needing to be made at the particular time, and in the case that capacity is found to be lacking, clear mechanisms by which others can make decisions on their behalf are set out.. Interventions, including making a decision on someone’s behalf, must be proportionate and consider whether the process and outcome of doing so, are the least restrictive of the person’s rights and freedoms. A detailed Code of Practice (Code) accompanies the MCA and sets out clear guidance on these and other matters.

The UK experience demonstrates a complex environment that required an investment of time, resources, consultation and planning over many years to embed real improvement, systemic and cultural change. Importantly, this process gained consensus across a wide range of stakeholders and has been welcomed by people using services, their caregivers and professionals. Following a European Court of Human Rights decision, the MCA has been strengthened by the passing of specific ‘Deprivation of Liberty Standards’ (DOLS).
The Act’s principles clearly set the tone, values and rights that underpin it and its operation:

- Assume a person has capacity unless proved otherwise.
- Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them.
- A person should not be treated as incapable of making a decision because their decision may seem unwise.
- Always do things or, take decisions for people without capacity, in their best interests.
- Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way.

The first three principles emphasise being able to make decisions for one-self, free of any stereotypes or biases and the last two guide those who may have to make decisions on behalf of another person.

I was very positive about the MCA and especially how the use of language, as well as the provisions, reframed the focus to capacity, rights protection and enablement. I had some concerns, however, about the degree to which decisions were left with potential providers or third parties (that may have a conflict of interest); this, notwithstanding the substantial safeguards of a comprehensive Code, exclusion of certain major decisions and the role of the Independent Mental Capacity Advocates (IMCAs). In the UK capacity is assessed by any person directly involved with the individual at the time a decision needs to be made. This might include attorneys, deputies, health professionals, care workers, paid carers, family members and service providers. The Code describes the responsibilities of those with a duty of care to a person lacking capacity, when acting or making decisions with, or on behalf of, individuals who lack the capacity to do these things themselves. The MCA allows a person to lawfully provide care and treatment to someone who lacks capacity if it is in their best interest, without reference to a tribunal or court process or other legal mechanisms.

Contrary to my concerns, most of the people I interviewed thought that this was working, with better outcomes for people living with a disability and a measurable shift away from protection to respecting an individual’s capacity (with support if need be) to assess the risk for themselves. (In fact, I noticed on the websites of some local authorities, the concept of risk enablement case conferencing or panels.) An alternate and minority view that I came across was that there was a lack of scrutiny of neither institutional placements nor accessible mechanisms for objection; and even when made, these may not trigger an external review of placements. They advocated for improved independent scrutiny of placement decisions and assessments of incapacity and of ‘best interests’.
Assessing Capacity

The UK MCA legislatives for a two-step process for assessing capacity.

The first step in deciding the applicability of the MCA and to assess capacity determines whether the person has an impairment of the mind or brain, or some sort of disturbance (either maybe temporary or permanent) that is affecting the way their mind or brain works? And whether this means that they are unable to make the decision in question at the time it needs to be made?

A second step requires an assessment of ability to make a decision and this test requires that, in relation to the matter at hand, a person is able to;- 

a) understand the information relevant to the decision (a general understanding of what is the decision they need to make and why? of the likely consequence of making or not making the decision?)  
b) retain that information, 

c) use or weigh up that information as part of the process of making the decision, and 
d) communicate his/her decision (whether by talking, sign language or any other means).

If the decision is more complex or serious – the need for a more thorough assessment by a doctor or other relevant professional must be considered. The threshold of proof required for acting on the basis that a person does not have capacity is “the balance of probabilities”. Judge Lush, Court of Protection (CoP) suggests the distinction is about ‘a person’s potential and the actual reality of their performance’.

Issues raised by several interviewees, including IMCAS were that: - 

- People can ‘talk the talk’ – making an assessment of capacity even more difficult 
- Assessing capacity is not an instant process – awareness of decision making difficulties may arise from observing a series of small decisions that overtime grow in number, complexity and the support required to implement them 
- Capacity can come and go away, and this might be for physiological or psychological reasons, circumstances at the time or the type of decision needing to be made 
- The ability for IMCA’s and others to accommodate all of the above and to make different or alternative times for or extend assessments -often within limited deadlines 
- Decision making is conceptualised as a rational, independent person “choosing” from a range of available options, based on relevant and sufficient information. But this is not necessarily the case; for many people with disability information may have been denied
them, someone else has always made decisions for them, or they have learnt to defer to authority figures or they may have already adapted or constrained their lifestyle (especially older people). In these cases the options available may have been reduced by them or for them by others – so what is the ‘norm’ for them in relation to personhood, lifestyle and history and in assessing decision making capacity?

- Not enough attention is given to the emotional side or the feelings involved in decision making. In certain circumstances, emotions play a big part in decision making and in these cases, they become the norm or driver of decisions not reasoned argument.

Hilary Brown noted the (expanded) use of the discretion to appoint IMCA’s in safeguarding matters, especially where there was family conflict and questions arise about whether decisions were actually in their ‘best interest’.

Safeguards
Where there is no independent person, such as a family member or friend, who can advocate on behalf of the person who lacks capacity an Independent Mental Capacity Advocate (IMCA) becomes involved in certain circumstances. This is when decisions are being made about serious medical treatment or significant changes of residences. Local Authorities and the National Health Service (NHS) also have the discretion to extend IMCA services to include accommodation services and adult protection procedures. IMCAs ensure that the decision making process is fair and takes into consideration the needs of the person fully. IMCAs are not a decision maker, they are there to represent and support the person who lacks capacity.

An IMCA can be instructed for safeguarding adults. This depends on whether an IMCA has been, or should be, involved for any other matter (i.e. a serious medical treatment or accommodation decision, a care review, or for one of the IMCA roles related to the DoLs). If so, consideration must be given to the appointment of another IMCA for this purpose.

Safeguarding issues might arise where a person at risk lacks capacity to consent to one or more of the protective measures being considered. These include where there is:

- a serious exposure to risks of death, serious physical injury or illness,
- a serious exposure to risks of deteriorating physical/mental health or of emotional distress,
- a life-changing decision involved and consulting family or friends is compromised by the reasonable belief that they would not have the person’s best interests at heart,
- a conflict of views between decision-makers about the person’s best interest,
- a risk of financial abuse which could have a serious impact on the person’s welfare (e.g. where a loss of money would mean that they would be unable to afford to live in their current accommodation, or to pay for valued opportunities).

**Best Interest Decision Making**

While *best interest* is not defined, a checklist is given for the decision maker, who must:

- involve the person who lacks capacity
- have regard for past and present wishes and feelings, especially written statements
- consult with others who are involved in the care of the person, and
- not make assumptions based solely on the person’s age, appearance, condition or behaviour.

The MCA does make it clear that decisions must be made in the best interests of those lacking capacity and that the decision maker must consider all relevant circumstances and avoid restricting the person’s rights. For practitioners, in complex cases, it can be hard to determine what would be in the person’s best interest. This is because the situations they find themselves in are ambiguous, with limited options or are ones that are dependent on the action of others - creating significant dilemmas.

Discussions with Hilary Brown (who was undertaking a review of complex cases (unpublished) for the Office of the Public Guardian) and staff from the Office of the Public Guardian informed me that;

- the two issues that most affected clarity (or lack of) about capacity, were fluctuations over time and the impact of who was present,
- steps that can be taken to mediate or address risk in these situations include instigation of safeguarding interventions, appointment of an IMCA, referral to a CoP hearing or for visitations and/or the appointment of an Enduring Power of Attorney, a welfare or financial deputy,
- the availability of financial resources can affect decisions about a person’s capacity and perceptions about the suitability of family (or professional )care arrangements, and
- family disputes and/or changing circumstances can disrupt arrangements put in place by the CoP.

This illustrates the ‘economic’, ‘relational’, ‘values/attitudinal’ dimensions that can affect the decision making of others and need for these to be taken into account in the practice of supported decision making and the development of necessary safeguards.
In our SA trial, we found that ‘who was present’ was a possible factor in the decision about joining or referral to our project and in acting on decisions made. Another challenge was how to deal with the intangible or less obvious forms of abuse or restrictive practice, either inadvertent or otherwise. These arise from having low expectations, placing limitations on a person’s daily interactions and activities, lack of developmental opportunities (including risk taking and making and learning or not learning from mistakes) and omissions (failure to act or put in place appropriate safeguards). These are harder to define, identify or act upon – but we know for many people with disabilities this happens daily.

Earlier in this report I noted that Hilary Brown (2003) suggests that people with a disability ‘are only vulnerable to the extent that their rights are not upheld or insofar as they are excluded from, or unable to gain access to, mainstream mechanisms for protection and redress’. This has implications for how we think about different disabilities and vulnerability.

**Differentiating Disabilities**
Failure to differentiate disabilities can lead to poor access, inappropriate responses by third parties, loss of rights, poor access to justice or other mechanisms for protection, redress and recovery. Unsuitable responses are often based on inaccurate stereotypes (refer to those reported by Brown (2003))\(^31\). The most challenging of these is where people with severe disabilities, who cannot verbally communicate, are denied neither adequate protections or assertive communication assistance because of entrenched stereotyping and labelling as being in a ‘vegetative state’.

Stainton (2005)\(^32\) describes this as the ‘difference dilemma’ and refers to the problem that ‘what people require to achieve an equal citizenship differs with each individual’. Equal treatment is insufficient, or a false logic, because people require different treatment and supports to achieve the ‘same basic capacity for participation’. Stainton goes on to say ‘equal capacity requires differential treatment based on differential needs to achieve the same relative capacity’.

Judge Lush stressed that people with cognitive disabilities, brain injury, mental illness or older people have different needs, requirements and considerations.

Why is this important? Because the UN CRPD and the moral status and personhood theories that underpin it emphasise that people with disabilities are equal in autonomy and legal capacity as everyone else. The risk is, especially for people with cognitive disabilities, that it may jeopardise the policies and services that entitle them and their caregivers to levels of protection and support that (might) exceed those afforded to others.\(^33\)
For example, specific policy responses may need to be developed for the following situations:-

- Where people might be targeted by ‘opportunistic people’, because their circumstances and disabilities are perceived to make them easy targets. In general, the law in these cases can be difficult to access and apply, but more so for people with some disabilities, who experience many barriers to accessing justice, through criminal and civil mechanisms, and consequently as ‘victims’ in seeking and obtaining redress or recovery supports. Specifically, all jurisdictions report that once financial resources are depleted through foul play, they are usually, gone forever.

- Poor financial circumstances, a perceived lack of credibility, cognitive and communication impairments and lack of knowledge and support to exercise their rights, pose additional barriers for people with disabilities that can lead to rights abuses, including loss of their legal rights and access to justice, redress and supports to recover. Too often, for the very same reasons, they are also unable to change or rectify the legal interventions, such as guardianship, that might compromise their rights.

- Within all population groups, some are more vulnerable than others. People with a disability and older people, for example, are exposed to risks arising from their service settings and poor or inappropriate responses to their dependencies or challenging needs.

In these situations, a lack of respect for their rights combined with poor access to justice and support in doing so creates a safe haven, for opportunistic people to operate ‘under the radar’. In such cases, prosecutions are rare, and convictions more so. Employees move on, or are moved on, when concerns about their standards of work are raised. I met with Martin Stevens, Kings College, London to discuss a scheme introduced to address this issue.

The Independent Safeguarding Authority 34 (ISA) was initiated by the Labour Government as a new vetting and barring scheme. It required all those working with vulnerable groups to undergo an enhanced vetting procedure before being allowed to commence any relevant duties, including people in domestic situations or employed through direct payments for support. After significant adverse professional, public and press reaction, in June 2010 the Coalition government announced that it would ‘scale back’ and abandon the apparent ‘assumption’ behind the scheme, that people were guilty until proven innocent and cleared to work with vulnerable adults and children. The amended scheme does not require registration nor retain details on a database and has a narrower remit. The exception is for those barred, whether due to a crime or ‘soft intelligence’ such as dismissal by an employer.
Of interest, was that the arguments mounted against this scheme were ones of access to justice, rights as a citizen and before the law and to privacy; the very rights often denied people with disabilities and which, create vulnerable situations for them. Other criticisms were that it created a 'climate of fear' while also creating 'an illusion of security'.

But the root issues here are; the training needs of personal assistants; robust systems for the monitoring of the standards of care; dealing with the less tangible or inadvertent potential abuses by relatives, paid and informal carers; supervision of people in such roles or acting on others’ behalf; and if, and how, the growing area of funded personal or domestic arrangements, should be brought into a regulatory framework.

On the topic of protection and vulnerability, a clear message I took from the UK was that a child protection paradigm for adults with a disability is wrong. For adults, it is exclusion from the wider community and the lack of close, trusting relationships and community bonds that expose people with disability to the greatest risks. Whereas with children there is evidence that abuse is likely to be from someone within their close relationships and/or intra-familial.

While a person with a disability cannot be adequately protected from neglect and abuse when experiencing exclusion, neither can they be left unprotected while ‘included’ – and this is both a challenge and a dilemma.

**Court of Protection and Office of the Public Guardian**

In England it is very rare for a substitute decision maker to be appointed through the Court of Protection (CoP). The CoP is able to make specific decisions or appoint deputies to make decisions on behalf of people who lack capacity. The general powers of the CoP are to:-

- Decide whether a person has the capacity to make a decision for themselves
- To make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make these decisions
- Appoint a deputy to make ongoing decisions for people lacking capacity to make those decisions
- Decide whether a Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA) is valid
- Remove deputies or attorneys who fail to carry out their duties
- Hear cases concerning objections to the registration of an LPA or EPA.
The MCA says the CoP should make a decision in preference to appointing a deputy, but that they can be appointed if a series of decisions are needed and a single CoP order is insufficient. There are three types of situations where a CoP appointed deputy might be required to:-

- make financial decisions
- make welfare decisions
- make both financial and welfare decisions.

The majority of matters before the CoP relate to property and financial affairs. Very few applications to the court are contested and approximately 95% of cases are handled procedurally; that is, the applicant does not need to attend a hearing. When the MCA came into force more applications for personal welfare deputies were expected, but this has not been the case. The MCA and the supporting Code both emphasise that personal welfare applications should only be sought as a last resort. Section 50 of the Act requires the applicant to seek the permission of the court before making an application. It was reported that such permission is refused in up to 80% of personal welfare applications.

The CoP is developing a body of case law to assist local authorities and other agencies to determine what is considered to be in the best interest of clients in complex situations. This seems a very useful direction. The challenge will be for others to use this without cutting across the principle of personalisation; individual will, preference and autonomy; and the unique circumstances surrounding the person and the specific decision needed to be made. It could be argued that supported decision making and the UN CRPD makes the concept of case law, around an individual’s unique decision making capacity, less relevant (as opposed to constitutional and administrative breaches).

In England the role of the Office of the Public Guardian (OPG) primarily revolves around financial matters. The key functions performed by the OPG are to set up and manage a register for both Lasting and Enduring Powers of Attorney and a register for court orders that appoint Deputies. The OPG supervises Deputies and instructs CoP visitors. It also receives reports from Deputies and Attorneys acting under the LPAs. When requested by the CoP the office provides it with reports when concerns have been raised about an Attorney or Deputy.

The OPG is not a substitute decision maker for either financial or personal welfare decisions. Unlike in Australia, there is no independent, statutory body who can act as deputy of last resort. The nomenclature of Public Guardian has a different meaning than in Australia, as its key role is as a regulator. Most deputies or receivers (for financial matters) are drawn from a panel of providers. There is interest in attracting community members to these roles.
Guidance on the practice of Supported Decision Making

After my visit to the UK I reflected upon the notion of supported decision making. For a start, these words do not even appear in the UK MCA or its companion Code, although the MCA would have been under consideration and development in the same time frame as the UN CRPD.

The practice, guidelines and principles are however predicated on this concept and approach, including that the statutory principles of the Act, which aim to

- protect people who lack capacity and help them take part, as much as possible, in decisions that affect them, and
- assist and support people who may lack capacity to make particular decisions, not to restrict or control their lives.

Further guidance, consistent with supported decision making on matters relating to decision making, is given in the Code:

- The non-use of excessive persuasion and/or undue pressure by anyone supporting a person who may lack capacity. ‘This might include behaving in a manner which is overbearing or dominating, or seeking to influence the person’s decision, and could push a person into making a decision they might not otherwise have made’. This is qualified by the statement that ‘However, it is important to provide appropriate advice and information’.

- Advice that providing appropriate help with decision-making should form part of care planning processes for people receiving health or social care services. One example is the Person Centred Planning for people with learning disabilities and this reflects my earlier observation about the availability of this in England.

- 3.15 states that in ‘some circumstances, individuals will be more comfortable making decisions when someone else is there to support them’. It advises consideration of whether the ‘the person (would) benefit from having another person present? Sometimes having a relative or friend nearby can provide helpful support and reduce anxiety. However, some people might find this intrusive, and it could increase their anxiety or affect their ability to make a free choice. Find ways of getting the person’s views on this, for example, by watching their behaviour towards other people’ and ‘always respect a person’s right to confidentiality’.
Section 3.16 discusses other ways to help someone make a decision for themselves:

- ‘Many people find it helpful to talk things over with people they trust – or people who have been in a similar situation or faced similar dilemmas. For example, people with learning difficulties may benefit from the help of a designated support worker or being part of a support network.

- If someone is very distressed (for example, following a death of someone close) or where there are long-standing problems that affect someone’s ability to understand an issue, it may be possible to delay a decision so that the person can have psychological therapy, if needed.’

There is no formal process or written agreement required (as in the Representation Agreement in BC Canada) but the MCA and Code says that a person can help people make decisions for them in their best interests by letting them know of any particular wishes and feelings. It suggests this could be in writing and given to professionals, carers, family or friends and that these are likely to carry weight. A person’s wishes and feelings must be considered when deciding what is in their best interests.

Another significant observation was that independent personal planning and supported decision making supports were widely available in the UK. Many organisations were providing this support or the resources, advice and training for people with disabilities and their families to do this for themselves. Local Authorities, a key provider of housing and social supports, appear to have embedded this philosophy and practice into their service planning and delivery frameworks. Personalisation or person centred service planning and delivery is a clear policy focus and appears to be well embedded into service delivery and systems. In addition, a variety of organisations exist to provide ‘circles’ of support, networks or friends. There is also substantial guidance on adult protection matters and a coordinated, collaborative inter-agency response as articulated in ‘No Secrets’ policy and guidelines.

An issue that sat uncomfortably at first, was that in England (as in Canada and elsewhere), if a person with a disability was on benefits and had no property or financial assets, there was no safeguarding against potential abuses, as they would not meet the criteria (of financial worth or assets) for any scrutiny. In England, as in Canada, the provider of benefits provides support to people with disabilities in the management of their finances, thus reducing a need for financial administration interventions.
While this reflects the least restrictive option, it seems to discount the value and importance to the person with disability, of their often small assets. I recollect a case where a person with a disability, who three or four times a year, purchased a new television. It turned out that his flat mate was selling on his televisions. Another, more frequent incident is people with disability being stranded at bus stops because others had snatched their tickets.

On the other hand, the Criminal Justice Act 2003 for England and Wales enables Courts to increase the sentence for offences shown to be motivated by prejudice and hostility based upon a victims disability or presumed disability. The 2009 Association of Chief Police Officers figures on crimes motivated by prejudice showed that of the 52,028 such crimes recorded, 1,402 were related to the victims’ disability. The potential under reporting of such offences can be appreciated by survey data provided by Mr Harmaaberg, Commissioner for Human Rights for the Council of Europe, which found 90% of people with intellectual disability had experienced harassment and bullying.

In response, the UK Government has established special measures such as services to help communication between the police and disabled adults with learning disabilities or mental health conditions during police investigations and interviews and allowing the presence of a supporter to the witness in a live link room. In England, Northern Ireland and Wales these services are on a statutory basis and in Scotland are under consideration. In Northern Ireland, the Criminal Evidence Act allows special measures to help disabled people give their best possible evidence, including permitting the prosecution ‘warm up' questions to help them relax before being cross-examined.

The MCA itself also sets up an offence of ill treatment or wilful neglect of someone who lacks capacity of any age. This applies to anyone caring for a person who lacks capacity to make decisions for themselves, including family carers, healthcare and social care staff in hospitals and care homes, those providing care in a person’s home as well as deputies appoint by the Cop and attorneys appointed under an EPA or LPA.

The MCA does not apply to any treatment being given under Part 4 - Consent to Treatment of the Mental Health Act. A person’s advance decision to refuse treatment for a mental disorder can be overruled if they are subject to compulsory treatment for the disorder.
Reflection: A Transformational Moment or a Paradigm Shift?

As cited earlier I had the opportunity to listen to others from around the world on the topic of Article 12 and supported decision making over 4 days in Vancouver, British Columbia. As I had already changed my thinking after my visit to Canada and the UK, this experience helped to both cement and transform some of these thoughts, which are set out below:

- The UN CRPD is about rights, obligations and human interdependence. It should change how we think about disability; away from medical, deficit or problem-oriented concepts to thinking of it as a ‘social construct’ and therefore, towards a deeper social understanding of disability and the interdependence of all human beings. It recognises that people with disabilities may need support to participate equally in society and obliges state parties to provide this as a matter of right to persons with a disability, not as welfare.

‘Human societies are built on the practice of interdependence. Whether disabled or not, support is part of the give and take, as well as, the emotional fabric of society’ (Amita Dhanda on Legal Capacity Article 12).

- A seed that had already been sown began to germinate. Article 12 is not just about guardianship. I had written similar in a previous paper;

‘The impact of Supported Decision Making though, is far wider than guardianship. It has the ability to transform how service providers, doctors, professionals and others, including family members, respond to people with disabilities and their wishes’.

In that same paper I went on to quote Gerard Quinn to illustrate this point.

‘……..what animates the entire UN CRPD is how others behave towards you’.

- Article 12 needs to be taken in its entirety and together with all the articles of the Convention. If guardianship reforms are the only outcome, then not much will have changed – it will be a new practice within the same regime, having moved between best interests, substituted and supported decision making. This is not to say reform in this direction is not needed, but we need to think both wider and simpler at the same time.

- A focus on guardianship legislation and reform and even supported decision making (SDM) can be an unhelpful starting point. Though not legally trained, I was attracted to universal enabling legislation combined with the requirement of others to make ‘reasonable accommodations’, including in other laws and policies. In this way all laws and policy
architecture will address, respect and provide for the support needs of people with disabilities in exercising their legal capacity (eg adult, child or consumer protection, contract, anti-discrimination, industrial and guardianship laws (if a ‘legislative option’), etc.).

- In part, this is how I had conceptualised the UK Mental Capacity Act to be operating – non - pejoratively and universal to all. It does not mention guardianship, focuses on the decision not the person and allows or mirrors what ordinarily happens in decision making; we seek the views of others close to us, give weight to, defer to or discount these views for a whole range of reasons, seek advice from ‘experts’ (a doctor, accountant, lawyer) in major, difficult or unfamiliar decisions and sometimes, we make wrong choices or mistakes that, (regrettably) we repeat time after time or maybe never do again. Often we make unwise decisions, but in whose eyes? The MCA does not put the decision making bar higher for people with disabilities.

- Attempting to clearly differentiate substitute and best interest decision making is thwarted by vague nuances, different interpretations and contexts. For example, substitute decision making has negative connotations because another person is appointed to make a decision on another’s behalf – the default decision maker. (In some countries this is plenary and forever). In South Australia, it means the decision to be made is the one that the person would make themselves (as if in their shoes) and avoids the paternalism implicit in best interest decision making. While, a decision or order needs to be one that is the least restrictive of the person’s rights and autonomy, it still needs to ensure ‘his or her proper care and protection’. (In fact the Act refers to a ‘protected person’). So there is also a best interest element to our SA Act. Most guardians consider that they already practice SDM. Legally, however, it is still the guardian that signs off, authorises, indicates or confirms a decision, regardless of the process used to discern it. The UK MCA uses ‘best interests’ but does define it. Instead guidance says it should reflect their past and present wishes and feelings and assist them to make decisions - not restrict or control their lives. This could be considered to be either a substituted decision or a supported decision.

- If traction and reforms for supported decision making are only part of a new guardianship regime, it will still be seen as an adult protection strategy, albeit more person-centred, but still within that jurisdiction’s providence. All the tensions of protection versus rights and thresholds for invoking guardianship would still mediate its practice.

- The more statutory steps and statuses involved in any regime will also mean that resources will be used in managing these boundaries, rather than in providing supports. For these reasons, the notion of a statutory continuum became less and less attractive.
Supported decision making, after all, is not even mentioned in Article 12 – it uses the words ‘take appropriate measures to provide access...to the support they require in exercising legal capacity’. Why had supported decision making become a noun, a practice rather than a verb and process? Why was the focus on supported decision making as a guardianship practice?

Can we legislate for a trusting relationship and friendship, for the long term – the kind that people turn to for wise counsel and support when they need to? And, which is given unconditionally? I think not, but we might legislate to enable supporters to be validly involved, to be protected from liability and for others to respect such decision arrangements. But then, if the role of a supporter is ‘institutionalised’, how do we prevent others looking to them for decisions to be made because of their ‘legal status’ and perhaps ignoring the person with a disability. Might it not just be a different, more universal approach to a form of guardianship?

Might it not somehow, relieve the onus on third parties to make accommodations when dealing with persons with a disability?

‘Dignity of risk’ requires people to have the opportunity to learn and alter their behaviour and this will often require support. Dignity of risk without support could be considered abandonment.

Article 12 and Article 16 - Freedom from Exploitation, Violence or Abuse are often linked together. Perhaps this reflects an orientation to adult protection rather than rights protection or simply a tension that is encountered every day in the work of a guardian. In South Australia, it more likely reflects a lack of separate legislation or a widespread interagency response framework for this purpose (adult protection). As a result people who may lack or have declining capacity might be placed under guardianship so they can receive an adult protection service- even though this might be more intrusive than need be. The system subordinates the right to make one’s own personal decisions to the right to personal safety - the right balance has not been struck.

An important conclusion was that placing support for decision making or even the discourse on what it means in practice within a protection paradigm, which most guardianship regimes conceivably are, will pervert the intention of Article 12 and the Convention. It needs to be freed from the constraints in our thinking that this might cause.

First and foremost it is about full rights and help to exercise those rights on an equal basis with others. This will have an impact in nearly every Article in the Convention and in every life domain of the person with a disability.

Decision making and using support in doing so, is a normal developmental process and reflects ‘life experience’ that is often compromised for people with disabilities, hence their perhaps initial need, for more support than some others. Access to support should
be a normal part of growing up, interacting with the community at large and forming relationships. Measures that increase this access and the validity of having a decision making supporter in a range of situations should be a policy priority.

- The perception that supported decisions might expose people to more risks, or the corollary, that guardianship is the ultimate protection, needs to be challenged. There is clear evidence that guardianship can fail to keep people safe and that along with other legal instruments such as an Enduring Power of Attorney or Guardian can be used as a tool for abuse or exploitation.

- Inclusion and social capital are the foremost protective factors for people living with a disability. This does not mean that they might not need protection while ‘included’; but if so, this can be provided by universal measures. These need to differentiate the needs and responses required of all population groups, including gender, age and disability, without limiting or restricting their rights and freedoms. Further, inclusion without social capital and support is abandonment.

- The safeguards discussed in Article 12.4 are about the measures taken to support a person exercise their legal capacity; to ensure that these are not abused or are inconsistent with international human rights law. While the measures are not defined, I prefer to think about them as positive protections that facilitate a person’s rights, interests and decision making, rather than negative protections that infringe, restrict or withdraw these rights and autonomy.

- Service providers, advocacy groups, funders, legislators, parents and the wider community need to adopt promote and respect supported decision making as a central tenet of disability or capacity related policy and practice. This will require community widening and development, attitude change and awareness.

- Services, whether specialist or mainstream must focus on individuals’ assets and capacity to flourish, not deficits; their aspirations and life plans as central drivers of the supports to be delivered; and creating a space for trying out, innovating and mistake making that is so often denied people with a disability. Access to improved personal and life planning processes, coordination and support is critical.

- Article 12 and the Convention envisage a positive transition and relationship with family from childhood to adult majority and associated rights; education, promotion and support to people with disabilities and their families will be needed to ensure this.

In the second stage of my Fellowship I had the opportunity to test these views with others, explore similarities or otherwise in their thinking and proposed systems and to investigate capacity building needs and strategies.
In September I reconvened my Fellowship, starting in Ireland where I was surprised at the number of people still living in congruent care, the dominance of the medical model and approach to disability issues and the system of ward ship that still operates. At the time of my visit, however, a schema for new legislation\textsuperscript{44} to modernise this system was under consultation. The role and views of the Centre for Disability Law and Policy (CDLP) was central to my observations as this Centre has been involved in preparing papers on Article 12 for various European forums, the United Nations and constituents in Ireland. They are interested in research on the implementation of Article 12 and the practice of supported decision making and were keen to hear about SA’s pilot.

In particular they have a view that mental health law, anti-discrimination and legal capacity, unlike in the past, should be considered together because of their overlapping nature and the artificial lines that had been drawn between these separate fields in the past. As indicated earlier in this report, Article 12 on legal capacity is considered to be at the core of the UN CRPD: Equal recognition as a person before the law is the key to the enjoyment of all other rights. Consequently, an assumption of legal capacity, the obligation on states to provide supports to people with disabilities to exercise their legal capacity are advocated as key tenets needed to be embedded in any new Irish law.

Similar to my previous reflections, they were concerned that the schema of the new Bill had a focus on regularising substitute decision-making in guardianship, instead of identifying and prioritising the supports that could prevent substituted decision making from being used in the first place and/or those that would augment a person’s decision making capacity. They suggest that where a person in question does not have any support network to assist with decision-making, the option of facilitated or co-decision-making should be considered rather than the imposition of substituted decision-making or guardianship. This reflects a continuum of support and assistance similar to that raised by Michael Bach for Ontario’s reforms (discussed at page 19) and the stepped model of supported decision making proposed by SA Office of the Public Advocate. (Appendix Three) A key issue is where does this support begin; as a step in a guardianship regime or as a consequence of wider disability and government policy.

Like in England, Australia and elsewhere, the new Bill makes reference to the wishes of a person, either previously or currently expressed. There is, however, no provision to legally enforce these wishes in future circumstances where they are deemed to lack capacity. This gives traction to ‘the best interests’ principle and the ability to override a person’s wishes – and this is inconsistent with having adult majority and associated rights. Article 12 requires the ‘will and preferences’ of the person to be the key determining factor in decisions about their life.

CDLP suggest that the primary role of a tribunal or court, is not to deprive a person of capacity, but rather, ‘to safeguard persons against deprivation of legal capacity (ensuring that
appropriate supports are provided for decision-making), protect against the abuse of persons considered to have impaired decision-making by third parties and ensure that safeguards that apply to supports are in place’ - A description not dissimilar to my earlier observations on positive and negative safeguards.

It was argued that the new Bill should also include provisions that would remove barriers that prevent persons with disabilities from living independently and acquiring the capacity to make decisions in all areas of their life. This reflects the large numbers of people with disabilities in Ireland that are still confined to congregate care and living arrangements. But it also points out the interdependence of all the Articles in UN CRPD. For example, the link between Article 12 and Article 19 \[\text{Article 12 and Article 19 }^{45}\] (living independently and being included in the community) of the UN CRPD is an important one (and a reoccurring theme). Without the latter, people with disabilities are being denied a very basic support in helping them exercise their legal capacity; that is living an ordinary life, full of the usual life experiences through which they can acquire the capacity to make decisions in all areas of their life, just like all citizens.

The following extract from CDLP’s Submission \[\text{Article 12 }^{46}\] provides an erudite explanation of Article 12.

The Paradigm Shift in Action

To illustrate the paradigm shift in Article 12 consider the legal capacity of the following:

1. Persons with a disability or an older person who can express their “will and preferences” have full legal capacity and the state should not interfere in the exercise of their legal capacity.

2. Persons with a disability or older person who with a range of supports can exercise their legal capacity should not be stripped of their legal capacity and the State is obligated to provide the necessary supports.

3. Persons who cannot express their “will and preferences” (following an accident/illness or have communication difficulties following institutionalisation) may require substitute decision-making, however, the State is required to ensure that decisions of others are policed and have regard to the “will and preferences” of that person.

Article 12 also requires a parallel commitment on the part of the State to restore or spark the capacity to make decisions through whatever appropriate means.

The CDLP submission identifies a broad framework or continuum of actions to effectively implement Article 12 of the UN Convention. Designed with people with intellectual disabilities and mental health difficulties in mind they suggest 8 key elements, which I have précised below.
1. **Advance planning**

A means by which people can let others know their “will and preferences” and who they wish to represent them prior to a future time or occasion when they may not be able to express their wishes. Enduring Powers of Attorney and Guardianship or Advance Care Directives are just some examples. These help avoid conflict or ambiguity and guardianship if at a future time, their decision-making capacity is compromised.

2. **Self-determined Decision-Making**

The Bill (in Ireland) should recognise that people with disabilities enjoy legal capacity on an equal basis with others, including the right to make bad decisions and to take risks. An obligation on professionals and service providers working with people with disabilities to have regard to this and understand self-determined decision-making needs promotion through a range of information and awareness programmes.

3. **Right to Information (including financial matters)**

Decision-making requires that all relevant information must be provided to the person. This right should be respected in all aspects of a person’s life, not just in decision-making. This will require shifting the locus of responsibility from the person receiving the information to those presenting the information to make sure that it is understandable to the widest audience. *(Notably in South Australia as elsewhere, information is often denied people with a disability or if it is, there is little support for them to access, understand and act upon it.)*

4. **Provision of a Range of Reasonable Accommodations**

This will be needed to assist the understanding of information given to people with disabilities. It might include technological equipment, sign interpreters, and accessible and easy to read formats. At meetings where decisions are made the person at the centre of the decision must be actively included and supported to attend and engage in deliberations. This includes their chosen representative attending on their behalf if they are unable to do so. The obligation to provide reasonable accommodation to persons with disabilities could be strengthened. The CDLP has identified the *Employment Equality Act, 1998-2008* the *Equal Status Act 2000-2008*, and the *Disability Act 2005* as starting points though there are many others.

5. **Provision of Advocate Support**

The support of advocates can enable effective decision-making. This might range from support for self-advocacy, peer-to-peer advocacy, citizen advocacy to more formal support in a range of ways including state appointed advocates and legal advocacy on areas of consent to treatment, health, housing and other issues. The CDLP suggests advocacy is a less restrictive alternative to the imposition of substituted decision-making, and statutory powers for advocates in the National Advocacy Service (Ireland) could be considered.
6. Supported Decision-Making
There is a need for a range of systems for supported decision-making, extending from informal supported decision-making to formal legal systems that ensure individuals remain present, do not become invisible before the law and where their rights and “will and preferences” are acted upon. The CDLP cites the Representation Agreement in British Columbia and the Personal Ombudsman system in Sweden as examples that could be adapted to the Irish context.

7. Co-Decision-Making and Facilitated Decision-Making
When all less restrictive support options have been tried and failed to resolve an individual situation, the circumstances in which substituted decision-making can be used needs to be spelt out. Co-decision-making or facilitated decision-making, are types of substituted decision-making that would comply with UN Convention. Their focus is on the “will and preferences” of individuals and not “best interests”. The appointed facilitator or co-decision maker must make the decision that comes closest to the “will and preferences” of the person and augment future decision-making capacity, however limited this capacity may at first appear to be. This process will take time. Article 12 .4 requires safeguards to be put in place so the support mechanisms described above ensure that the rights of the person are protected throughout the entire process. The role of a court or tribunal could be to ensure that every available less restrictive alternative has been attempted before co-decision-making or facilitated decision-making is used as a last resort.

8. Financial Rights
Article 12 (5), is very clear about abuse of rights in respect of inheritance, property rights, day to day control of financial affairs, equal access to bank loans, mortgages and other forms of credit. Measures are needed to promote an understanding of the financial rights of persons with disabilities, to them and others. In Ireland, Banks have the authority to determine their own rules, which create hurdles in this area. CDLP suggests this could in part be addressed, by a requirement in the Bill for the development of national standards that respect the capacity of persons with disabilities.

(A similar situation exists in Australia. To my knowledge the area of financial reform, as proposed in Ireland, is not being addressed as part of a response to UN CRPD though I know this issue (of individual banks setting their own rules) arose in a recent review of advance directives in SA. Guardians also encounter different processes and rules, making their work difficult. The application of trusteeship and financial administration orders are other necessary areas of reform needed in Australia. (This is discussed later in this report at page 82.)

The CDLP has also undertaken work on Article 12 and Mental Health law and policy. This to my knowledge is an area that to date has not been given the same attention in Australia. This may
reflect that in Australia, most states have fairly recent and modern mental health laws. One interpretation of the UN CRPD is that to be compliant, State Parties will need to end coercion and dismantle laws that provide for involuntary detention on the basis of having a mental disorder and support every citizen in exercising their legal capacity. The repeal of involuntary detention and treatment laws in Ireland and other countries is unlikely (Australia’s declaration stated that this was considered not to be inconsistent with the UN CRPD); however, steps can be taken towards meeting the obligations under international human rights law.

Discussion on the Mental Health system in Ireland with CDLP and others identified a number of issues and ideas for law reform and system improvements. Although not always on the topic of Article 12, these and their links to the UN CRPD where applicable, are summarised below.

- Move to a system that truly respects the voluntary nature of the decision to undergo treatment and provide effective safeguards for this process.

- Reduce the use of involuntary admission and help it to be the absolute last resort, by providing effective, accessible and ongoing supports in the community, including
  - crisis and recovery supports,
  - multidisciplinary home-based and assertive outreach care, and
  - a comprehensive range of relevant medical, psychological and social therapies for services users and their families.

- Apply and strengthen the principles of autonomy and empowerment, through
  - recognising the vital role of a peer advocate in supporting individuals through mental health treatment,
  - introducing individual care plans that carefully set out the steps required and to be put in place for recovery and community integration,
  - increasing the use of advance directives, so a person can indicate their will and preferences,
  - adopting a presumption of capacity and definition of the best interests that accords with the UN CRPD,
  - consulting with and supporting the active participation of the person in all decisions about their care and treatment,
  - ensuring a person has access to support in situations where capacity issues arise, and
  - adopting the principle and practice of supported decision making to enable people to make their own decisions, wherever possible.
While the current mental health law enacts clear processes and safeguards (currently under review) for the involuntary detention of patients, this is not as true for voluntary patients. A seemingly compliant but incapacitated person may not be truly voluntary; they may not have been asked and if so, been able to give or freely given informed consent for admission or treatment. Assistance with decision making that they may have required at the time it was made (or at successive times) may not have been identified and provided.

While much discussion of UN CRPD and mental health issues centres around the validity of forced detention for treatment, the discussion and pro-active framework presented by CDLP on voluntary admission and the UN CRPD, puts this into a different context and addresses ‘root causes’. In this framework, it is taken that UN CRPD suggests that a presumption of capacity should apply to all voluntary admissions, with consideration given to their capacity to make the choice or decision and access to a decision making supporter or supports provided to augment a person’s decision making capacity – at the time. The premise is that the more confident people are about the system, its procedural and rights safeguards and the integrity of the principle of the least restrictive (or absolute last) alternative, the more likely they might seek and stay in touch with services, of their own genuine volition. Improvement in the conditions for the therapeutic process and recovery will be a further, significant benefit. (i.e. people will not superficially comply with or evade treatment to avoid committal and will genuinely engage in the therapeutic process).

The above approach turns the discussion of forced treatment on its head, and provides a useful, proactive platform for the debate on forced treatment.

In the opening observations, Ireland’s antiquated disability laws and services were mentioned. One example was raised over and over and reinforces that every country is responding to UN CRPD from different starting points, contexts and motivations.

In Ireland, the Criminal Law (Sexual Offences) Act 1993 creates an offence of having a sexual relationship with a person who is mentally impaired. Legal advice to provider organisations suggests they would be in breach of their duty of care if they permitted persons in their support to engage in sexual activity or have an intimate relationship; thus generating a fear of criminal liability. As a result, people with intellectual disability are effectively prohibited from entering into intimate relationships. Apart from legal arguments about the meaning of “independent living” and possible discrimination, in relation to the UN CRPD, it ignores a person’s “will and preferences” and subjects people with intellectual disability to a higher test of capacity for consent to sexual relations than for others.
In respect of the UN CRPD and mental health law, another area of potential law reform that requires consideration is the defence of mental incapacity or incompetence (commonly known as the insanity defence) on the grounds of cognitive disability or mental illness. While I gather it is not a focus of current law reform proposals in Ireland, I was able to engage in dialogue on the topic with researchers at the CDLP and others.

The importance and relevance of this issue, as a consequence of Article 12, was highlighted at the international seminars held in Vancouver, British Colombia, Canada. A pure response to the UN CRPD would mean that the presumption of legal capacity would make this defence redundant. Some disability organisations hold this position. The rationale for such a defence is that it avoids the application of punishment (historically capital punishment) for conduct that a person was not responsible for at the time of the commission of the offence. The objective elements of the act must always be proven as well as the alleged offender’s mental incapacity (or other definitions) at the time of the offence. Sentencing under these provisions includes detention for the purpose of treatment. (In South Australia, release on license with supervision is also a ‘sentencing’ option). In many jurisdictions, this involves an indeterminate period of detention and associated with this, concerns about the quality and standard of treatment and rights abuses that ensue. Understandably, in such situations there will be valid objections to the outcomes of this defence. Many people feel that this defence, especially when over used or used as a first resort, serves to criminalise people with disabilities, especially in the eyes of the public. It also can give the message that people with disabilities, can or are not capable, of accepting responsibility for their actions.

Conceptually, this is a challenging and difficult area of the law. Modern approaches to this defence are based on solid and well accepted principles of justice, human rights and civil society; arguably a more just and humane response to crimes committed by people with a mental impairment - with recovery, treatment and rehabilitation being the primary social and justice outcomes. But like in South Australia, the period of detention or supervision, may exceed that given for the same crime, if the person did not have a mental impairment and did not use this defence, or indeed had they raised their state of mind or mitigating circumstances for the court’s consideration (an option open to all). For example, depression on the loss of a family member, leading to a first offence of shoplifting with a possible outcome of no conviction being recorded on condition that they seek treatment or counselling. Would not simply substituting proof of ‘mens rea’ for proof of mental incompetence suffice? That is, proving a prior intention to commit an act, with the knowledge that the act was a crime.

The injustices experienced by people with disabilities due to not having access to justice as victims, witnesses, plaintiffs or civil litigants are enormous, let alone the further victimisation they experience as a result. To have an equal footing before the law, in all aspects of the law
(with necessary support, or accommodation) - is a defining rights issue, which conceivably far out way the benefits of a defence based on disability, especially when there are universal defences and judicial and sentencing options, available to all regardless of disability. Various court diversion programs are also available and do not rely on a person being found mentally impaired or incompetent.

Another discussion in Ireland was around the terminology ‘person centred planning’. Is personalisation of services synonymous with person centred services or planning? This struck a chord, because experiences in South Australia showed that the response of providers and to a degree the person concerned, interpreted this to be self-centred or selfish: A recipe for disaster, especially when living in a communal or family environment, regardless of the presence of disability or otherwise. Person centred seems to ignore the interdependencies of humans and the need for give and take as individuals and civilised society.
In Hungary, guardianship and capacity laws are in need of substantial reform. This, despite Hungary being one of the first to sign the UN CRPD and to review and draft new legal codes in line with it. Unfortunately, at the very last minute, these failed to come into force.

Hungarian guardianship legislation dates back to the 1950’s. I was told that between 65,000-80,000 people are under guardianship (approaching 1% of the population) with 2 out of 3 people being under plenary guardianship of some form. The provisions governing guardianship are spread throughout a number of statutes and regulations in their constitutional and legal architecture. While the Constitution provides for the respect of the human rights of people with disabilities, in practice there is little differentiation or understanding of the needs of people with psycho-social and intellectual disabilities and poor services, guardianship practices and human rights orientation. There is little monitoring of guardianship practices, outcomes and possible abuses.

A brief snapshot of the guardianship system precedes a discussion of my primary interest which was the change process and the facilitators and barriers to it experienced over nearly a decade.

Guardianship in Hungary:

- Affects your rights to work, property, family life and marriage, to vote and freely associate, to decide where and with whom you live and to access the courts.
- Many of the large number of adults living in institutions were placed there by their guardians, irrespective of their wishes.
- Measures are often put in place based on a diagnosis of mental illness or disability without an assessment of functional or decision making capacity
- The laws relating to guardianship are vague, complex and inconsistently applied with inconsistent outcomes.
- The process is arbitrary, lacks procedural clarity and due process and can lead to significant deprivations of human rights.
- The law neither guides nor obligates a guardian to promote the person’s independence and inclusion in community life.
- No alternatives to guardianship exist - it is the first and only response to people who may need decision making assistance.
- Other legal instruments such as advance directives or powers of attorney do not exist
- There is little or very poor access to information, advice and representation for the adult at the centre of the determination or about the human rights implications.
- Professional guardians may have 100 people under their guardianship and in the case of some large institutions many, many more than this.
A Decade of Momentum and Change:
A reactionary and incomplete reform of guardianship provisions occurred in 2001 due to criticism from the Ombudsman’s Office and civil society organisations. The new (2001) provisions limited the remit of guardians to certain matters (handling money, disposing of property, healthcare or family). The former types of guardianship (plenary and partial guardianship) still remained and in practice, these continued to be applied by the courts - not the new less restrictive options - at the same rate as before. There was little change: the definition of legal capacity and the medical model of disability prevailed and the right to vote denied people with disability under guardianship. This right would not be won until the definition and basis for legal capacity was changed and the Constitution amended.

I was told that an (unexplained) hiatus followed these minimal changes and as a result the expert group drafting the new Civil Code continued to do so on the basis that there was no need or appetite to address the issue of legal capacity. This changed in 2007 during which time the following events occurred:-

- Hungary signed the UN CRPD
- The Mental Disability Advocacy Centre (MDAC)\(^{51}\) released a second and follow up report on Guardianship in Hungary
- Government agreed that reforms needed to go further and announced that the Ministry of Justice would now be responsible for drafting and consulting on the new Code.

A coalition between the MDAC and non-government organisations continued to monitor and advocate for reforms, including through publishing reports and discussion papers, seminars and international engagement.

On 22 September 2009 the Hungarian Parliament voted for a new Civil Code that banned plenary guardianship and provided for ‘partial’ guardianship; in specific areas of decision-making and through joint decision making between the adult and the guardian. Supported decision-making and advance directives were also introduced.

There was however still scope and advocacy for further reforms to improve consistency and compliance with the UN CRPD. Some of these were:

- A broader definition of disability, inclusive of persons (or labelled) with psycho-social disabilities
- Removal of the Constitutional prohibition on the right to vote for adults without full legal capacity
- Measures to reduce the numbers of people in large residential institutions and for the creation of a wider range of community services
• Strengthening the independent monitoring of the UN CRPD by transferring responsibility for this from the National Disability Council to the Parliamentary Ombudsman and providing appropriate resources for it to fulfil its mandate

• Ensuring that a Government minister oversees a "focal point" to coordinate disability policy across Government departments.

In March 2010 a Member of Parliament petitioned the Constitutional Court to declare the paragraph making the legal capacity rules enter into force on 1 May 2010, unconstitutional. Arguments were that the preparation time for lawyers, judges and others was too short and the two stepped process with different proclamation dates would cause confusion and the violation of legal certainty. The Hungarian Constitutional Court accepted these arguments and annulled its entry into force indefinitely. Around this time, parliamentary elections were held and a new government took up office in June 2010. There is an expectation that a new Civil Code will be reconsidered after extensive revision and a longer time devoted to preparations.

The following was reported to me about the initial process (that is the 2001 partial reforms):

• The procedure leading to the 2001 provisions revealed a generally low engagement of civil society in law and policy reforms and/or inexperience in doing so

• This highlighted an undeveloped capacity of civil society actors to influence matters of public interest

• While there was open consultation how much influence civil society had is unclear. Two contributing factors suggested for this are that (1) the process was not transparent and (2) civil society input was disparate and uncoordinated. As a result many disability organisations submitted conflicting recommendations

• Opinions ranged from family organisations wanting guardians to have even more control through to intellectual disability and psycho-social organisations wanting more freedom and autonomy for persons with disabilities.

Hungarian disabled peoples’ organisations, however, continued to monitor the implementation of the amended law and concluded very little had changed.

MDAC became involved in a multi-country guardianship research project, which showed that Hungary’s 2001 laws, contrary to government’s position, did not meet relevant international standards.
The negotiations and resolutions of UN CRPD (between December 2001 and March 2007) were gaining increasing attention, especially universal legal capacity and the right to supports for decision-making. MDAC and other Hungarian NGOs, who were in this process, tried unsuccessfully to educate and shift the views of Hungarian authorities.

MDAC launched part one of its report on Hungarian Guardianship in 2006. This event was attended by representatives of international organisations and academic institutions, Hungarian disability people’s organisations and government, including from the Ministry of Justice. This process was lauded because of the authority, expertise and momentum garnered in support of radical change to guardianship and human rights law.

In 2007, MDAC established a coalition of about 20 NGOs, mostly DPOs, with the objective ‘to reform law and policy related to legal capacity’. This was supported by funding from the Trust for Civil Society in Central and Eastern Europe.

By mid-2007, this coalition had completed a legislative proposal based on the UN CRPD and Article 12. Over about a year the Ministry of Justice informally consulted with the coalition’s representatives MDAC and ÉFOÉSZ (an intellectual disability umbrella organisation) with the result that their work became the basis for the government’s legislative proposal. At the request of government, the coalition continued to submit legal text in support of reforms.

This process was not immune from challenges and resistance to the Coalition’s work. Several Supreme Court Judges opposed any proposal to abolish plenary guardianship; in their view some people with disabilities would always ‘need’ plenary guardianship. Strategies to thwart the legal proposal included intense lobbying to maintain the out-dated system of guardianship based on their view that the current system complied with the UN CRPD requirements and opportunistic legal argument centred on an ambiguity arising from the translation of Article 12 into Hungarian.

Parliamentary consideration of the proposed new Civil Code was tempered by continuing resistance to the abolition of plenary guardianship and a politically motivated reluctance to express support for it by some MPs. To counter this, the Coalition prepared and disseminated information about the new laws and the positive impact it would have on the lives of people with disabilities and society as a whole. It has already been explained that the Bill was eventually supported in 2009, but annulled after a successful petition to the Constitutional Court in 2010.
Drawing on discussions, reports and reflections on this history, the following provides a summary of the factors considered to have had a positive impact on change;

- Collaborative effort, drawing on the experiences and expertise of different organisations and the primary stakeholders
- Involvement of disabled people’s organisations, and the provision of support and assistance to them, if this is needed and wanted by them
- Building the skill and capacity of people and organisations, to engage in policy-making and creating opportunities for this purpose, e.g. roundtables, seminars and workshops
- Government adopting more open, inclusive and transparent processes for initiating, consulting and developing policy
- Co-ordinated, galvanised action, such as that of the Coalition, around a central issue
- Good, clear information and use of effective dissemination channels
- Resources and sponsorship
- Evidenced based research and systems analysis as in the MDAC Project Reports
- Forging links and networking with academics, technical and practice experts
- Engaging with others with similar or even very different experiences to share information and garner support
- Optimising or leveraging from international connections, with the aim of broadening exposure to other ways of doing things and expanding the thinking around possible solutions and the status afforded to these propositions
- A supportive response from the media between 2005 and 2007, initiated by a highly motivated journalist who mobilised colleagues and produced a number of first person stories and critical writings on the state of guardianship in Hungary
- Enlisting legal colleagues in preparing the legal text – on the basis that, if the language and this expert resource could be given to government, there might be less resistance.

A MDAC report\(^5\) says the ‘participation of NGOs representing persons with disabilities in the preparatory work of the new Civil Code, and the extent to which the expertise of civil society organisations was relied on and valued by legislators, was an experience which most Hungarian civil society actors have never witnessed before.’ Further, it demonstrates the benefits of embracing the ‘new disability politics encouraged by the (UN) CRPD’. There was also a concerted effort to develop workable solutions, in the context of where Hungary was starting from; illustrated by a number of matters that were not in accord with the UN CRPD being put aside for tackling at a later stage in secondary legislation.
Other important factors were, the UN CRPD itself, Hungary becoming a signatory to it, having Hungarian representation at the UN CRPD committee levels, regional alliances through the EU and the influence of the European Court of Human Rights. Both in Hungary and in the Czech Republic strategic litigation was frequently mentioned as a lever for advancing reforms. The Hungarian experience of codifying new guardianship laws has been influential in developments in its neighbouring country, the Czech Republic (CR).
The Czech Republic (CR)\textsuperscript{53, 54} shares a similar but more recent history with Hungary in the evolution of guardianship reforms. In January 2009, through the efforts of a coalition for reform, between MDAC, NGOs and the League of Human Rights (LIGA) the CR Ministry of Justice proposed reforms to the Government. This introduced alternatives to guardianship, general advance directives (not only those appointing a future decision maker), supported decision-making, representation by next-of-kin in common affairs of daily life and guardianship without limitation of legal capacity. After much debate and advocacy plenary guardianship was also deleted from the draft law and this was eventually agreed to by government.

Provisions guiding the conduct of guardians were also added, for example, the obligation on them to keep in touch with the person under guardianship, explain, in an appropriate manner the nature and consequences of decisions taken by them, and to take into account his/her opinions (including any advance directives which have previously been made) in the management of their affairs. The agreed draft Code anticipated that provisions regarding public guardians were to be regulated by a separate law and established a ‘guardianship council’ as a safeguard; a right for the person under guardianship to participate in the meetings of his or her guardianship council, to appeal its decisions; and to receive (together with the court and the guardianship council) annual and ad hoc financial accounts of their property. In March 2009, the Czech government lost a vote of no confidence; however the draft Civil Code was still submitted to the Lower Chamber of the Parliament. In the last session of Parliament prior to elections in autumn 2009, the Civil Code was removed from debate. Since then, the CR ratified the UN CRPD, which came into force 12 February 2010. The Ministry of Labour and Social Affairs became the national focal point for issues relating to the implementation of the Convention. A new ‘National Plan for Creating Equal Opportunities for Persons with Disabilities 2010–2014’\textsuperscript{55} was approved by a ‘Resolution of the Government of the CR’ in March 2010. This foreshadowed changes to the substantial and procedural laws in line with the UN CRPD.

In Prague, I met with representatives of QUIP\textsuperscript{56} - The Association for Change in the Czech Republic. Founded in 2003, it aims to support the development of good practice in social services, promote education and raise awareness of the rights of social service users, especially those with learning difficulties and complex needs. They reported that new regulations introduced in 2007 endorsed the following agenda and principles for disability services:

- Purpose of social services: social inclusion
- Individualization: planning and financing – allowance for care
- Protection of rights
- Quality: inspection and quality standards
- Community planning
- New models and types of services and regulation of prices.
However, they reported that while some good outcomes have been achieved, other anticipated benefits have not always been delivered. The various outcomes include:

- Reduction of restrictions and more attention to fulfilling rights
- More emphasis on people’s rights, individualisation and integration of services
- Poor understanding of quality standards and the implementation of inspections
- Financial implications for the whole system, especially for NGO providers, resulting in instability and disruption (care allowances, price regulation, community planning funds)
- Consolidation of old forms of services – institutions and statutory facilities now ‘homes’ but change in name only and the continued building of new, large, high capacity institutions

Some barriers to de-institutionalisation were identified as:

- Restrictive legal capacity and guardianship practices
- Poverty of people with disabilities
- General acceptance of institutional care as adequate support for people with disabilities
- Lack of political initiative and no plan for deinstitutionalization.

As with the discussion of Ireland’s reform process the link between Article 5 - Equality before the Law and Article 19 - Living independently and being included in the community is very important. The latter is a basic pre-condition for developing decision making skills and forging relationships with potential, conflict free decision making supporters in their lives.

QUIP\(^7\) has a comprehensive agenda and strategy to support reforms and build the capacity of services, professionals and people with disabilities. These are:

**A focus on sector development in the practice of personalisation**

QUIP had recently received funding from the European Social Fund to identify and promote best practice across Europe. The focus chosen for this work was the personalization policies and practices, being embedded in the England. QUIP was being supported by In Control, UK in these endeavors. QUIP provides the following advocacy and support services:

**Education for a Change**

The main part of the organisation’s activities is the education of social service providers and establishers. QUIP offers training for direct service providers as well as for management in social services and brings in international experts to assist them to do this, with the aim of:

- enhancing professional skills and knowledge of staff so that they can improve their work for social inclusion of people with disabilities into the community life.
- enriching the local practice with the latest approaches and methods of work.
• educating professionals, service providers and users in legal matters related to providing of social services, including guardianship and human rights.

Legal support of social service users and providers
QUIP assists service users and providers to deal with legal problems and rights issues such as the legal status of people with disabilities. This includes
• respecting and realization of their human rights and freedoms
• legal capacity
• exercise of guardianship
• social inclusion (education, work, and disability pensions)
• responsibility of providers and users, and
• rights and duties arising from the law on social services.

They are involved in promoting the rights of people with learning disabilities and complex needs through influencing the legislation and government and regional policies concerning this group of people. It also is involved in legal advocacy on matters relating to the application of the law and procedural justice.

Promoting of good practice
QUIP does this in the main through two awards. The first award, promotes to the wider community real examples of inclusion of handicapped people (not only people with disabilities) into common society. They join with RYTMUS Civic Association, to give an award to people who have accepted ‘personal responsibility for the life of a disadvantaged person’ and have helped them access the same possibilities of access or redress as those without apparent disadvantage. A second award, ‘Hope for Change’ recognises work teams from social care institutions and their activities, which lead to changes that raise the quality of life and social inclusion of people that still reside in institutions.

Measurement of service efficiency
QUIP has also been developing software (eQuip) for providers and establishers of social services for the evaluation of the efficiency of services provided to people with disability. The evaluations can then be used for continual improvement and linked to the strategic plans of the organisation. eQuip has other functionalities which can assist day-to-day management, improved staff and client databases and the meeting of quality standards for social services.
Information dissemination and exchange

QUIP's web portal [www.kvalitavpraxi.cz](http://www.kvalitavpraxi.cz) provides up to date information on issues, publications and resources to professionals and to people with learning difficulties and their relatives and friends. This is provided in accessible formats. By cooperating with professionals and other experts it publishes and disseminates through this portal information and methodologies on supporting the exercise of human rights of people with disabilities.

Projects

With the assistance of various sponsors QUIP is also involved in a number of projects. One such project is the Inspiration Project. This aims to gain inspiration from foreign innovations, bring this experience into the CR and enable other countries, usually new EU members to draw on this and the CR experiences. Currently the project encompasses two yearly international conferences on quality of life and individualisation of services; opportunities to participate in work groups on international activities; study tours for a group of lecturers and other professionals to Germany and the UK; thematic networks to enable testing of the In Control a Supported Brokerage tool in the CR. Three foreign partners participate on the project: European Coalition for Community Living; the Siegen University and In Control Partnerships, UK. These activities and the production and dissemination of information aims to support, innovation, sustainability and mainstreaming of project activities and outcomes.

The New Paths to Inclusion project is about transferring skills and experience in ‘Person Centred Planning and Practice’ from the UK to the vocational education and training and service systems in six European countries: Austria, Germany, Czech Republic, Slovakia, Italy and Luxemburg. As an outcome of the project a training module on inclusive Curriculum and Training in Person Centred Planning and Practice will be developed and a course presented in in Czech Republic, Germany and Austria.

In both the CR and Hungary during interviews a number of issues were raised as barriers to better guardianship practices. Briefly these included the following comments;

The dominance of the medical model, with assessment of needs done by medical officers

- Historically there are low levels of trust in society, and yet SDM is predicated on trust
- Inspectorate systems not working well - big differences exist between regions as to who are, how it is done, the frequency and the training of inspectors (CR)
- Guardianship providing an automatic place in an institution for support services (CR)
- The nexus between guardianship and being placed in institutional care, usually without choice or any consultation
• Complexity of legal codes

• A number of funding related issues, such as
  
  - Perversions associated within the allocation of disability benefits (such as these being paid automatically to guardians)
  
  - Benefits and funding to organisations being paid on the basis of medical conditions and diagnoses not needs (CR)
  
  - A system of annual grants to provider organisations keeps the process political and entrenches out-dated thinking and service models, keeping the power within 5 big institutions (CR)
  
  - Unequal system of funding for NG and government service providers
  
  - Lack of dual funding during process of transformation or de-institutionalisation
  
  - Lack of effort and resources to develop the community services network – and for in meeting the needs of people already in institutions

• Family tensions and problems which may not fit well with the SDM paradigm and therefore the need to support or improve family relationships through, say counselling and/or mediation

• Just like with guardianship frameworks, adult protection rationales or processes could deviate the process and outcomes from the path needed to achieve UN CRPD outcomes

• The same illusions about the protective functions of guardianship apply to adult protection frameworks

• The need for accessible, high quality and independent advocacy and peer support

• Public education and awareness and community development is needed

• Lack of community services impedes progress

• Better training for professionals and others involved with people with disabilities

• Political instability

• Poor mechanisms for dealing with possible corruption

• The complexity of having three levels of public administration – state, regional and district -all with varying roles and capacity in service delivery, inspection and regulation and guardianship (CR).
In **India** transformational change is in progress, with consideration of ‘The Rights of Persons with Disabilities Bill, 2011’ underway. This is enabling legislation, akin to a charter of rights for people with a disability, to which other legislative measures such as guardianship must overtime be harmonised. It has a strong community widening and development focus.

This Bill is the outcome of a comprehensive consultative process with people with disabilities, their advocates and representative organisations, civil society, service providers, academics and the legal fraternity and all levels of government through all India and its states. This process of awareness raising and consultation in association with developing new legislation, is a first for India, and demonstrates the spirit and principles of the UN CRPD have been embraced.

‘The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995’ will be replaced by the new Bill. While this 1995 Act has advanced empowerment and the rights of persons with disabilities, which will be retained in any new Bill, it does not address a number of rights recognised in the UN CRPD or where it does, inconsistencies with the principles of the Convention need to be clarified.

The Indian government set up a committee for this purpose with the following Terms of Reference for the Committee drafting the new legislation were;

- To ensure that the New Law should be in harmonisation with the UN CRPD
- To keep in view the provisions of the Constitution and other laws, and avoid duplication of provisions already existing in them
- To give the financial, logistical and administrative feasibility of the proposed provisions
- To give the financial implications…recurring or non-recurring on the Central Government, State Government or other Local Authorities for implementing the new statute.

On the Committee’s recommendation, the Centre for Disability Studies, National Academy of Legal Studies and Research (NALSAR), Shamirpet, Hyderabad, India was appointed as Legal Consultants to the Committee.

**Key Principles and the Structural and Legal Components of the New Bill**

A report on the Bill, summary of the consultation process, issues identified and justification can be found at [http://socialjustice.nic.in/pdf/report-pwd.pdf](http://socialjustice.nic.in/pdf/report-pwd.pdf). The following is a summary including salient extracts from that Report.
Principles

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The new Bill introduces a new paradigm on legal capacity based on the presumption of legal capacity, equality and dignity: This paradigm is one that -

- recognises that persons with disabilities are an integral part of human diversity, enriching it with their vision, their experience & their creativity.
- provides a vehicle for ensuring participation in society on an equal basis with others,
- seeks an equality of outcome by recognizing multiple discrimination faced by women and children.

This is consistent with the fundamental tenets of the UN CRPD; the social model of disability, universal legal capacity with support and no forced interventions. The proposed Bill recognises all three and makes them the driving force of disability rights. Consequently, the development of a socio-medical scale, new regimes of support and alternatives to institutions for persons with disabilities are mandated. Currently, these do not necessarily exist, so a range of transitional arrangements, on matters such as the definition of disability, guardianship and compulsory care have been made firstly, to avoid a legal vacuum and secondly, “to ensure that the values of the new paradigm inform the transitional period”.

The statute also recognises that for persons with disabilities needing high support and for those in aggravated circumstances, pro-active efforts would be required to get them their just due.

High Support is defined in the new Bill as:-
‘that support, which may be needed by individuals who require ongoing intensive support for activities of daily living; independent and informed decision-making; accessing facilities and participating in all areas of life including education; employment; family and community life; treatment and therapy; recreation and leisure. The need for high support often arises due to
significant disability in a single area or multiple or cumulative disabilities in cognition, communication, sensory – perceptual processing (not including blindness), emotional regulation, socialization, behaviour and mobility in interaction with attitudinal or environmental barriers’

Legal Framework
Persons with disabilities were in the contemplation of the makers of the Constitution only as recipients of charity. It is important therefore that the Constitution of the country refers to persons with disabilities as full citizens who cannot be discriminated against on grounds of disability, including the removal of any disability prejudicial references, for example, “disabled and the unemployable” and “handicapped and mentally retarded”. It also suggests that in Articles 15 and 16 of the Constitution disability needs to be specified as prohibited grounds.

Importantly the Bill provides for matters which are not addressed in the Constitution, because the “rights guaranteed by the Constitution need adaptation to be of value for persons with disabilities”. An example of this in practice, is that without accessibility and reasonable accommodation the “right to equality and non-discrimination is of little value to persons with disabilities”.

The Bill foreshadows that the National Trust Act, the Rehabilitation Council of India Act and the Mental Health Act, amongst others need to be harmonised with the Bill and UN CRPD. It is proposed that this can occur when the new Bill is enacted as well as prejudicial disability references in all other laws being replaced by the disability rights approach.

It was noted that past legislative provisions and judicial decisions (precedents) have in effect not included persons with disabilities as an ‘essential party in the matter(s)’ and deny certain rights such as legal capacity to them. Consequently, the Bill was formulated without reference to these, but rather contemporary philosophy and legal writings and of course, the UN CRPD.

Structural and Administrative Changes
With the aim of proactively pursuing the rights of persons with disabilities and to deal with the disability intersections between Ministries, the Bill recommends and provides for some key administrative changes. Amongst others, these include the creation of a Ministry on Empowerment of Persons with Disabilities; all major schemes and programmes of the Government of India (GOI)I are to include a component of disability; and a requirement that all relevant Ministries ensure the comprehensive coverage of children with disabilities. It was also recommended that all government authorities / organisations should have a Disability Experiential Expert and a Disability Cell. This makes the “appropriate level of government, concerned establishments and individual persons, responsible for fulfilling the obligations of the statute.”
A Disability Experiential Expert is defined in the Bill as a person with disability who has through personal experience, advocacy intervention or service provision acquired expertise in relation to the impairment and the related barriers; or a family care giver who has through personal experience, advocacy intervention or service provision acquired expertise in relation to the impairment and the related barriers.

A Disability Cell refers to the establishment of a Disability Rights Cell in all appropriate governments and establishments to coordinate the implementation of this Act.

The new Bill protects people with disabilities from discrimination, rights and other abuses by:

- guaranteeing equality and non-discrimination to all persons with disabilities;
- recognising the multiple and aggravated discrimination faced by women with disabilities and inducting a gendered understanding of rights and the programmatic interventions;
- recognising the special vulnerabilities of children with disabilities and ensure that they are treated on an equal basis with other children;
- mandating proactive interventions for persons with disabilities who are elderly, confined to their homes, abandoned, segregated or living in institutions and also those who need high support;
- dismantling structural discrimination existing against persons with disabilities;
- enforcing due observance of regulations promulgated under this Act for the protection, promotion and enjoyment of all rights guaranteed in the Act; and
- specifying civil and criminal sanctions for wrongful acts and omissions.

The Bill establishes the following bodies:-

- National and State Disability Rights Authorities, to facilitate the formulation of disability policy and law, with active participation of persons with disabilities.

- Disability Rights Tribunals at District, State and National levels with powers to:-
  - hear complaints and grievances
  - remedy by removal of the practice or scheme
  - discontinue any activity in violation of the Bill
  - award compensation to the victim for any loss or injury suffered
  - provide adequate costs to the party.
  Depending on the matter each level can escalate a matter to the next highest level.

- Disability Rights Defenders, as a panel at of each District Disability Rights Tribunal.
Changes to the National Trust Act were not decided at the time of my visit. There was speculation that it would become a Trust for providing high support to persons with disabilities and would, amongst other functions, have a focus on legal capacity and supported decision making. It was suggested that the latter might include activities to create

- accessible support networks (material, technological or otherwise) to help people exercise their legal capacity in all areas of life
- an active community of support, including organisations, parent groups, peer, community support and self-advocacy programs
- a cadre of persons providing support to people with disabilities
- systems for monitoring support regimes
- programs for transitioning from guardianship to new supported arrangements, including mediation, awareness raising and education for existing guardians in communicating with people with disabilities, informed consent and supported decision making
- new support and personal planning mechanisms
- a repository for resources so that people with disability can chose to voluntarily register their support plans with the Trust.

It was envisaged that existing Local Level Committees might be reconstituted to include roles in transitional arrangements, assessment and oversight of guardianship arrangements, assistance to develop more wide ranges of support and promotion of the scheme to public spirited individuals. They could also have a safeguarding role in terms of consulting directly with persons with disabilities about the quality of the support they are receiving, maintaining open communication with support providers and facilitating community interaction, mutual learning and information sharing on innovative or good practice models. State Level Committees could provide further safeguards, by;

- dealing with complaints against a local committee,
- monitoring the implementation of programs and schemes for persons with disabilities,
- ensuring coordination,
- provide training and education, and
- collating data, statistics and findings of local committees.

Support planning arrangements might include advance directives (in the form of a living will or by proxy), Enduring Power of Attorney, instructions for personal assistants, supported decision maker, care plans, any combination of these and so forth.
Observations
As background to the following observations and discussion, it needs to be understood that the proposed new Bill and any concomitant changes to other Acts would replace, retrospectively and prospectively, any legislation, rule, regulation or practice that establishes plenary guardianship, with a system of limited guardianship. This is defined as ‘a system of joint decision making which operates on mutual understanding and trust between the guardian and the person with disability’.

Further it states that
‘Any act, order or proceedings which has the effect of denying the legal capacity of a person with disability in any matter or which questions the legal capacity of a person with disability on the grounds of disability shall be void; and

Upon a person with disability being denied legal capacity, the aggrieved person with disability may file a complaint before the District Disability Rights Tribunal in addition to other statutory or constitutional remedies.’

The legislative reforms that are being considered in India are genuinely progressive and transformational. They enshrine in legislation all the principles of the UN CRPD, and importantly embed these universally, in government processes and in the life, dynamics and interactions of the wider community.

At the time of my Fellowship visit the Bill had not yet been passed and brought into force. This and its development have not been without disagreement, debate and opposition. The following commentary is based on what I observed and what was reported to me.

Parent groups and some associated organisations that I met with were opposed to the proposals to harmonise guardianship legislation and the National Trust Act (the Trust Act) with the new Bill. Primarily this could be attributed,

- the potential loss of natural guardianship rights of next to kin,
- loss of hard won rights of the groups that lobbied for and are currently covered by the Trust Act, (people with autism, cerebral palsy, mental retardation and multiple disabilities) and for which the Trust came into being - ostensibly to cater for the situation when in a future time parents of children/persons with these disabilities would no longer be around or able to care for them,
- following on from this, a great deal of unhappiness with the use of the generic descriptor “high support” in both the new Bill and any other Act, should they be similarly amended,
• the broadening of the Trust Act to include people with other disabilities (who may not have the same needs) and particularly, intense opposition to it including people with mental illness,

• loss of focus on the needs of the groups that the Trust Act was originally established to assist, arguably the most disadvantaged in Indian and other societies,

• a failure to differentiate the needs, circumstance and opportunities of people with various disabilities (net widening) and in respect of legal capacity, and

• no confidence that the Bill would result in additional resources to cater for wider disability population and expanded unmet needs, as a result of the proposed changes.

Service providers in India are usually parent led organisations and rely on family support (usually the mother) to be actively involved in their program delivery and activities and fundraising. This is so in urban communities, and even more so in rural communities, where a lack of services means it is often the families’ total responsibility without any other support. Having said this, in India there is a dearth of provision and access to a range of services that are taken for granted in many developed countries.

The parents (and their representatives) I spoke to, closely aligned with the provider organisation of choice, found the new system ‘insulting’ in that it failed to recognise their role, commitment, time and resources spent in supporting their son or daughter – with very little practical or financial support from government. Indeed it was said to me, ‘if I am not good enough to be their guardian, (government) can do the personal care, supporting and the ‘picking up of the pieces’ of failures or adverse events’ both those currently encountered and anticipated to accompany the proposed changes.

Given this, there was intense feeling that supports and services needed to be provided before attention to rights and self-actualisation, rather than meeting them contiguously. The benefits of the community widening and development aspects of the new Bill were over shadowed by the negative reactions to the potential changes to the Trust Act.

There was an expressed view that the abolition of substitute decision making (and plenary guardianship) was not appropriate for people with severe or profound disabilities, but might be so for people with mild disabilities, depending on their circumstances. The benefit of SDM giving clarity to informal arrangements was considered not relevant to the Indian context, because these were the default and accepted position.
Nevertheless, in India (as within some other cultures) the willingness or possibility of fulfilling kinship responsibilities is gradually being eroded. People are moving from rural to urban settings for employment and lifestyle considerations and many more between Indian states and global destinations for tertiary education and employment. The latter can lead to emigration and the further weakening of kinship ties. In some respects the new proposals anticipate these societal changes and put in place arrangements that will stand regardless of these trends.

On the other hand, some of the opponents to the anticipated legislative amendments to the Trust Act were the very ones actively engaged in progressing reforms in relation to UN CRPD and in particular, Article 12 and supported decision making. There seemed to be solid support for the disability rights Bill, but not so for any change to the Trust Act. A number of pilots were being conducted across India under the auspice of PARIVAAR to develop good practice in supported decision making. A consistent view expressed to me, was that time and ‘little steps at a time’ were needed rather than radical reform. I was told that India’s response, in practice, to a vast range of human rights issues has not been good in the past - therefore why should people with disabilities wear the brunt of such rapid reform?

I met with a volunteer SDM Project Coordinator in New Delhi, who described the efforts and the training being provided to people with disabilities, their families and volunteer supporters. Initially, I thought some of the examples, such as transport training, did not fit with supported decision making, but quickly, given the status and context of services in India, realised its significance and why there was advocacy for a softly, softly approach. It also reminded me of the intangible and inadvertent barriers to the development of capacity (and life experience) encountered by people with disabilities generally and by our own SA SDM Trial Project Coordinator. This is why the UN CRPD is so important – it will eliminate the barriers and expand the opportunities for people to exercise capacity in all areas of their life.

I was told how people involved in this project received training. People with a disability, their parents and volunteer supporters attended training sessions where a clear message was ‘to lift the ceiling’ on their view of their son or daughter’s capability. In this project I understood that the volunteer supporters had two roles, to expand life experience and build skills (eg transport training) as a foundation for decision making and become supporters in decision making. Participants and supporters had a Facebook Group, where they shared experiences, lessons in life, skills and decision making challenges. I was impressed with the volunteers’ energy and commitment. Also their awareness of how they as supporters, (even mentors or “idols”) might in-avertedly influence the decisions of the people they were supporting and their conscious efforts to avoid this and to carefully check out the ownership of the decision.
Past history, poor access to a range of services and underdeveloped service options (unmet basic needs), familial and cultural considerations and expectations, competition for funding and services, the potential for net-widening for scant resources and fear of the most disadvantaged in Indian society missing out or getting less all came together to temper a more positive response to the changes that might flow from harmonising the Trust Act with the new Bill. On the other hand, I was informed that people with disabilities themselves, their representative groups and advocates supported the proposed changes and some even thought that these did not go far enough: For example, they objected to the inclusion of limited guardianship.

An irony is that in Australia some view that we comply with Article 12 of the UN CRPD but welcome its emphasis on safeguards from abuses arising within these regimes. One argument against further reform (in Australia) is that the UN CRPD is primarily for less developed and antiquated regimes in countries with poor human rights protections. Yet, in India, an argument posited for slower, less radical reform, was that it suits countries with well-developed modern regimes and support services, like Australia, and is too advanced for countries that do not have these and established, government funded support services.

While the proposed structures proposed to support the implementation of the new Bill and other related changes may seem administratively cumbersome, readers must consider that India’s population is currently 900 times that of South Australia and 60 times that of Australia. Further, India has approximately 3.3 million of land mass compared with about 7 million square kilometres for Australia.

A very strong focus of India’s proposed reform is that of community development and engagement in supporting inclusion, capacity development and decision making rights for people with disabilities. The proposed structures support community initiative and widening for this purpose, including programs that provide peer support and advance self-advocacy.

Of interest the new Bill (Rights of persons with Disabilities) foreshadows the intention to develop a socio-medical scale, ‘...to examine the interplay between a particular impairment and the scale of the barrier experienced by the persons with disabilities’. This is quite an innovative concept consistent with the social model of disability. Most other assessment tools or scales, tend to measure a person’s deficits, level of dependencies and for funding hours of support or services required for basic care needs.

This scale will potentially break down any conflicts based on perceived needs related to diagnostically defined disabilities and arguments against an inclusive broad definition of disability.
5 Conclusions

Some thoughts and deductions have been discussed along the way in this report. In this section, these have been briefly revisited along with a more fulsome description of the main findings and conclusions of my Churchill Fellowship.

When finalising this report, I came across a report from the Office of the Children’s Commissioner, New Zealand on child poverty. One of its papers attracted my attention; while not about Article 12 or the UN CRPD, it explained unequivocally its importance.

By Associate Professor Manuka Henare it quotes a report, He Ara Hou: The Pathway Forward that describes a ‘Capabilities Approach’ as one that ‘....addresses human rights and social justice, and offers better systems for Maori and Pasifika to evaluate the effectiveness of policies in terms of well-being for themselves.’ Referring to the same report Henare, suggests the approaches required for a sustainable environment are also required for humans; - ‘....i.e.to sustain the potential of humans, by safeguarding their capacity and combating adverse effects.’

It refers to Meri Ngaraoto, a Te Aupouri tribal leader of the early 19th Century who believed that ‘humanism and reciprocity is a philosophical duality that informs the ethical and moral basis of living a responsible life and a life of obligation that constitutes a good life’. It points out the similarity between her thinking and Amartya Sen ‘...who maintained that a truly developed society would enable humans to be and do, and to live and act, in certain valuable ways. Both actual achievements and the freedom to achieve are intrinsically valuable ingredients in a good human life’.

The paper goes on to discuss development aid and its focus on commodities and material needs, concluding (that) ‘someone whose basic needs are satisfied would still be poor if his/her potentialities as a human being were not sustained’.

There are four overarching conclusions to my Fellowship studies and from which all others follow.

The first is that whether countries are rich or poor, developed or undeveloped – the key issue is whether policies, community dynamics and society at large allow, support and enhance human potential - for all. Rights, freedoms and respect for human diversity, are essential elements of well-being.
The second is that there is only one choice in relation to legal capacity. Amita Dhanda suggests that legislators have two potential choices; one ‘recognises that all persons have legal capacity’, the other ‘contends that legal capacity is not a universal human attribute’. Universal capacity acknowledges that given the opportunity, all human beings can grow and develop or conversely, a ceiling or limit on their universal capacity, will deny them the opportunity to do so. I agree with Dhanda’s view that opportunity for growth and development has to be given to all persons and therefore, law and policy must create options and opportunities for this - for all.

The third is that policy discussion and action on legal capacity and Article 12 has to be wider than just guardianship.

- Article 12 is not just about guardianship. It needs to be taken in its entirety and together with all the articles of the Convention.
- Evolving decision making capacity through support is a normal developmental process, reflects ‘life experience’ and human interdependencies that are often compromised for people with disabilities.
- Article 12 is about enabling and creating opportunities for people with disability to take part in and derive experience from living a full life (and removing any limits to this).
- An element of Article 12 that is not given enough attention is the obligation on States ‘to restore or spark the capacity to make decisions through whatever appropriate means’.

The fourth, flowing naturally from all of the above, is that the mire of legal complexity and debate can be reduced to a far simpler proposition: All adults capable of controlling their affairs, on their own or with assistance, have legal capacity. This should be the default position.

- This and the social model of disability must be the starting point for any reforms.
- Rather than tweaking the existing ‘binary’ approach to capacity, the focus needs to be on achieving the human rights conferred by the UN CRPD in total.
- This means providing the support, assistance and accommodations required, so that people with disability can make decisions and act on their rights.
Foci of Change

The primary focus of any legal architecture must be to protect and enhance, not take away, rights and legal capacity. Nor should it subordinate any of these rights to antiquated notions of protection; ones that do not respect or accommodate human diversity, lead to loss of autonomy and personal freedoms and are based on ‘disability’ as a problem or deficit and on inaccurate stereotypes.

Canada and the UK, having embraced community living and universal adult protection legislation and systems, are now advancing a vast array of legal capacity, supported decision making and other rights initiatives. In Canada this includes savings and pension (or superannuation) schemes for people with disability. Hungary and Czech Republic, with historical plenary guardianship arrangements, institutionalisation and constitutional impediments to change are focussing on legal reform. Both have used human right defenders to strategically litigate rights abuses. Access to the European Court of Human Rights for claims against administrative and constitutional breaches is a valuable advantage. Other strategies include education and capacity building; exposure to fresh thinking and expertise; and public awareness and promotion - underpinned by the strong involvement of people with disabilities and user led organisations.

Ireland is currently considering proposals to change their guardianship laws consistent with supported decision-making. However there is a view that without legislating for community rather than congregated living, the most basic support for legal capacity and the capacity (and opportunity) to act, will continue to be denied people with disabilities. Advocates seek for these issues to be addressed concurrently in any reform. In all countries visited, most guardianship reforms include some form of limited guardianship but with the proviso that safeguards enhance, not limit, decision making and legal capacity. Often these are considered as necessary, transitional arrangements on the journey to more empowering and liberal approaches to legal capacity. This also enables the necessary supports to be developed and introduced over time in tandem with capacity building of services and the community at large.

India is tackling a range of integrated elements through comprehensive, systemic reform. Proposals exist for the introduction of legislative and administrative provisions, with the aim (amongst others) of:

- enabling the participation of people with disabilities in the life of the community and to enjoy freedoms, rights and opportunities on an equal basis with others;
- enhancing rights and rights protection, including through access to human rights defenders;
- facilitating community awareness, education, engagement and development;
- monitoring of implementation;
- facilitating innovation and disseminating good practices;
- developing more and better access to advocacy, peer and mediation support;
- legitimising supported decision making;
- developing and expanding avenues of support;
- establishing tribunals focussed on rights protection;
- universalising rights to protection, recovery and redress; and importantly
- breaking down the social constructs of disability and barriers to inclusion, with increased accountability for this within government and across the wider community.

Strategies aim to lessen the burden on families and ensure measures take into account emerging social and demographic trends and their impact on traditional family based arrangements.

Australia is a signatory to the UN CRPD and its Optional Protocol, indicating its commitment to a rights focus and giving people with disability greater choice, control and independence. Australia-wide developments include a National Disability Strategy (NDS), a National Disability Agreement (NDA) and the exploration of a National Disability Insurance Scheme (NDIS) by the Council of Australian Governments (COAG).

In South Australia, a blueprint for reform, Strong Voices was recently completed. One of its recommendations was for new (state) legislation, with a stronger rights focus, with clear avenues and support to report breaches or grievances and to redress. (The existing Act is more administrative in nature). The following, is a preface to this recommendation, from that report.

>'Visionary, robust and rights-based legislation is a key foundation to progressing disability reform. Legislation needs to be enabling for individuals and systems, and provide enduring assurances. A strong rights-based legislative foundation drives change in community attitudes and practice. It acts as a catalyst for service change and setting standards of accountability. It can effectively reduce the barriers facing people with disability. Importantly, legislation assists individuals, governments, employers and private and community sector organisations to effectively plan for the future with confidence.'

At both the state and national level, the rhetoric surrounding reform proposals, includes personalisation of services; individual funding; assistance with planning for required supports and making choices; and ‘activation of the community’.

To summarise, in Australia, there is an emerging platform on which to build comprehensive and integrated reform. To my knowledge, any change to guardianship legislation (except in the state of Victoria) is not being considered. This is a significant lost opportunity that may well result in contradictory philosophies, practices and unintended consequences and also to the distraction (and cost) of legal debate and arbitration.
A Whole of Systems Response

The development of a ‘systems’ response to UN CRPD requires setting aside the question of whether a person has or has not legal capacity (and any stereotypes of disability) and all else that accompanies it. Disability and other government policies and services, for profit and not for profit providers and the wider business and professional community, need to embed and popularise practices and supports consistent with supported decision making and legal capacity. Necessary accommodations, programs and models might be required for different situations. These need to be tested and developed alongside of education, community awareness raising and capacity building for families, services, supporters, third parties and the public.

An important element is access to assistance with planning for one’s own life and achieving personal aspirations. Such support is under developed in South Australia and elsewhere in Australia; too often persons with disability must fit into what is available, focus on their deficits and present to services/funders in the worst possible light in order to gain access to basic support services. This creates further dependence rather than giving voice to their abilities (often untapped), life plans, choices and aspirations. Independent planning support and advocacy are needed to grow opportunities, help set and achieve life goals and enhance their capacity to act.

The practice of supported decision making and personal planning and self-determination are closely linked. Supported decision making can facilitate and be a tool and safeguard to ensure people with disabilities making their own plans and choices in life wherever possible.

- Community widening, attitude change, awareness and development are close companions to supported decision making.
- Services must focus on:-
  - individuals’ assets and capacity to flourish – not on deficits
  - people with a disability as subjects - not as objects or welfare recipients
  - the person with a disability and their aspirations – where their life plans are central drivers of the services to be delivered
  - creating the space for trying out, innovating and mistake making that is so often denied people with a disability.
- All government agencies and instrumentalities must have pro-inclusion, pro-rights and pro-legal capacity policies and practices and be made accountable for these.
- Independent monitoring of practices and robust and accessible complaint systems must be part of the system.
- Greater access to independent support planning, free of conflict of interest must be available to people with disabilities so they can exercise and act upon their legal capacity.
The above is especially true, if individual or direct funding for services are to be introduced; firstly, to enable people to make and act on choices about services and secondly, to ensure all people with disabilities have access to such systems.

An investment is required in the types of supports required for decision making and which can deliver a sense of community connectedness, belonging and participation for people with a disability.

Involving and Bringing Family along the Change Journey

While Article 12, UN CRPD is about adults and their rights, the relationship between family and a person with disability is an important one, especially in the development of decision making skills and opportunities for life experiences that will enhance these skills.

To a large degree, how receptive families are to this and the concept and of legal capacity will depend on how well supported they feel in providing such opportunities, letting go and in ‘picking up the pieces’ of mistakes made or adverse events. Having to fight for, or live without inclusion and the normal experiences of life (and the normal protections and avenues for redress) and a lack of services will be barriers to the acceptance of legal capacity, notions of autonomy and free will. So many families are left to struggle with the barriers encountered by their son or daughters with a disability and consequently, experience exclusion as well. It would be difficult for them to give credence to a life of inclusion, a more accepting approach to capacity and the willingness of others to engage with, get to know their son or daughter and support them in decision making.

Where family are making decisions under informal arrangements, these will be placed on a firmer footing and their role and the decisions supported will be respected with less bureaucracy and red tape and without having to seek guardianship simply to overcome administrative or legal obstacles. In these cases, both family and person with disability will gain.

With supported decision making as opposed to guardianship, people living with disability will have more personal authority in their lives and more active inclusion in the life and transactions of the wider community. As a result, their capacity and confidence in doing so will grow with many positive benefits for them and their families.

Article 12 and the Convention envisage a positive transition and relationship with family from childhood to adult majority and associated rights. This does not mean it will be without all the usual challenges associated with this transition.
■ For confidence in any new scheme (s) it will be important to promote to families;
- benefits arising from pro - legal capacity policies for their son or daughter,
- the supports and safeguards available to help them exercise their legal capacity, and
- how any new arrangements will provide for when they, or other relatives, might not be available to support and provide care for their family member with a disability?

■ Many people with disabilities will choose family as their supporters in most of their life domains – and through supported decision making arrangements, these will be placed on a firmer footing, without legislative interventions or bureaucracy. In some circumstances or for specific decisions, family may not be the chosen supporter, just like for people without a disability. The transition to adult majority requires change and concessions on the part of the young or soon to be adult and their parents: It is a two way street.

■ This might require access to mediation and counselling to resolve sticking points or conflict, rather than an imposition of guardianship that interferes with a person’s legal rights and potentially diminishes or impedes the development of capacity in decision making. Further, it reflects a power imbalance that is not appropriate to adult to adult relations.

■ SA’s SDM trial would benefit from seeking funding to extend its pilot to include a specific focus on those transitioning to adult majority and their families and also, as a voluntary alternative to private guardianship arrangements.
Supported Decision Making: Parameters and Practice

Supported decision making is based on the free agreement of the adult (with a disability) and their chosen supporters. There may be many more supporters (or a network of supporters) than exist under traditional guardianship arrangements; the important element is that of choice.

The priority for policies, funding and interventions must first and foremost be to facilitate and enable such relationships to be developed naturally. Community development activities that help to recruit and engage community spirited people in the lives of people with a disability are also important. Appointing unknown ‘supporters’ under a statutory scheme seems to cut across the integrity and philosophical base of supported decision making. This is not to say, there might not be a need for highly trained and skilled ‘decision specific supporters’: For example, in instances where it is difficult to determine a person’s wishes and they appear to need support, or where support efforts have failed. Access to people skilled and trained in establishing communication, augmenting capacity and respecting autonomy could help not only the person with a disability but any other party to the decision to be made. The question is does this form of support need to be within a guardianship framework? If there is to be an appointed decision supporter, they should be differentiated from a chosen supporter. The distinction here is the natural/spontaneous, voluntary or appointed nature of the relationship, which in turn informs the foci and level of needed safeguards.

There will be people with disability without friends or family or who have relatives that are unwilling or able to be a supporter. In these cases effort must be made to help the person establish or re-establish supportive relationships that may overtime develop into decision making support arrangements. In this case the arrangements are a ‘hybrid’ form of support; either ‘facilitated’ network building for supported decision making or where a person may have agreed to having a volunteer, unknown to them, to initially take on this role.

All jurisdictions visited were advocating for the promotion of advance planning for support that people might need in the future. India included this as one of the possible decision making supports to be available to people with disabilities. The assumption of legal capacity (with support to exercise legal capacity) would suggest that existing barriers to making advance directives (i.e. incapacity) no longer exist. Similarly, Canada gives priority to a representative agreement over an advance directive if a person has both.

The view of the International Disability Alliance (IDA) 73 is that

‘A person may agree with his or her supporter(s) that the supporter(s) can make certain types of decisions, should the supporter be unable to determine the person’s wishes at a particular time. This does not mean that the person loses his or her right to make those decisions. The supporter is bound to keep making the effort to communicate and to follow the person’s wishes as far as they may be known’.

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Conclusions
Proposals in India suggest that a support plan could be any or a combination of a range of components. The Advance Directive component could be those that

- let others know about their life choices, will and preference, so these prevail over all their affairs, especially if they were not available and others needed to managing their affairs, or
- appoint a person (proxy) to make certain decisions for them in particular life areas that they would prefer someone else to do, or
- a combination of both; a proxy appointed to act in line with explicit provisions given.

As with the IMCAs in the UK or the proposed rights tribunals in India - safeguards are required to ensure all steps have been taken to facilitate a person’s decision making and that the process honors their potential to make decisions, now and in the future.

Examples of practice considerations have been discussed throughout this report (refer pages 23 - 26 and 29 - 31). Some key issues identified or emerging are:-

- **Communication**: If a supporter is not known to the person with a disability or familiar with their communication style and preferences, than it will not be easy for them to understand their will, preferences and past and future wishes. This will take time. Words and expressions can mean different things to different people.

- **Non-verbal presentations**: These create their own complexity and can give an incorrect view of a person’s capacity. The limitation of the supporter, such as their experience of the person and their history and in augmenting capacity, can influence decision outcomes. Picture communication when used, has its limitations.

- **Knowledge of a person**: It is difficult to gain sufficient knowledge of a person’s history or to ascertain their preferences at a single point in time and or relevant to a single decision.

- **Time restraints and timing of interactions**: These pose problems for assessing capacity and gaining an understanding of a person’s will and preferences; insufficient time, the nature and timing of matter raised and whether it can be dealt with in a planned or sudden fashion.

- **Relationships**: Those present and their relationship will affect how the person with a disability presents and responds. Some might behave as usual or as ‘expected’ by whoever is present, or indeed the opposite, others might comply or acquiesce because of the person’s relationship to them, authority or position and others simply to ‘please’.

- **Past experience and opportunities**: Expressed preferences may be based solely on what they know or have been allowed to do in the past, lack of accommodations and denial of opportunities, life and decision making experience and personal development. (e.g. ‘(he) living outside an institution for the first time, when faced with a choice of breakfast cereals, decided to try them all, living only on cereal for many weeks so as to discern his favourite’.)
• **Context:** The decision to be made and presence of other factors such as property, financial resources and the immediate impact of the decision are all factors that might cloud capacity and influence the decision making, of the person and others views. Emotions and feelings associated with the decision or matter at hand also need consideration.

• **Rights:** Lack of knowledge about what is the ‘norm’ for others and of their rights pose serious impediments for a person to discern and express their preferences.

• **Access to Information:** This is so often denied with a disability (to ‘protecting them’) and poses a serious impediment to decision making. Access to information needs to be in all areas of life not just related to the decision needing to be made. We know that information giving at the time of an important decision is likely to be ineffective. Anecdotes abound about professionals and others, deciding not to provide salient information or consult with someone because it would ‘not be in their interest’ or ‘they would not understand’.

• **Support to act on decisions:** This can come in many forms, including physical access, coordination of supports, personal planning, community integration opportunities, individual funding and ‘reasonable accommodation’ by third parties, creativity of providers or simply permission. Service or funding limitations is no excuse for people not being empowered to make their own life choices.

All of the above have implications for both natural and ‘unnatural’ supporters.

- These highlight the benefit and need for access to independent personal planning services; advocacy and peer support; and mediation and counselling options.

- Assistance may be needed to help a person establish or re-establish supportive relationships that may overtime develop into decision making support arrangements.

- Decision making supports, safeguards and decision making environments or contexts, need to be sensitive to these factors so that a person’s will and preference presides.

- The merit of an independent resource organisation similar to NIDUS (or as in India through their anticipated local structures), especially in the early days of promotion, capacity building and implementation of guidelines for practice and safeguards.
Safeguards

The safeguards required by Article 12 are about protecting a person’s legal capacity, their right to make decisions for themselves and their access to supports to do so, if need be. They need to ensure that the decision and the support and trusting relationship that helped a decision to be made reflect the person’s will and preference, are not a matter of abuse nor lead to further abuse or exploitation and are respected by other parties.

- The primary safeguard to be provided by parties to the UN CRPD is meeting their obligation to provide supports for decision making and ensuring that others provide the necessary accommodations and respect decisions made in this way.

- The best support for decision making is inclusion and living full lives. Policies, funding and interventions must facilitate and enable natural, lasting, trusting and supportive relationships to be developed in the first place.

- Safeguards are required to ensure
  - legal capacity is not deprived
  - support is provided to make decisions and to exercise and develop legal capacity
  - decisions made (including saying no) are respected, and
  - possible abuses (of decision making support) by third parties or supporters do not occur.

This is arguably a reversal of priorities within many current approaches to legal capacity.

- The need for safeguards is not debated; rather, how they are decided, put in place and uphold rights, autonomy and capacity for personal development? Paternalism, well meaning, or otherwise, usually operates in a way that infringes these capacities and rights.

- Brown (2003) suggests the following safeguarding (against abuse) schema, which can apply equally well for abuses of decision making and legal capacity.

**FIGURE 4: SAFEGUARDING SCHEMA**

<table>
<thead>
<tr>
<th>LEVEL of Intervention</th>
<th>STAGE of Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td></td>
</tr>
<tr>
<td>Service providers, funders, procurers</td>
<td>Measures to: Prevent abuse from happening in the first place - across all levels. Information &amp; education are critical</td>
</tr>
<tr>
<td>Whole of Government &amp; community</td>
<td>Measures to: Identify abuse, refer to right agency, intervene and stop it re-occurring - across all levels. Robust, accessible complaints systems are critical</td>
</tr>
<tr>
<td></td>
<td>Measures to: Treat &amp; help people to recover, avoid problems allied with trauma &amp; distress - across all levels. Data collection and analysis are critical</td>
</tr>
</tbody>
</table>

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Conclusions
Protection

In any consideration of safeguards the following issues must be taken into account

- Adult protection is the wrong paradigm for legal capacity
  A focus on the vulnerability of persons with disabilities and their need for protection is an unhelpful starting point. It can distort the debate and stifle rights enhancing mechanisms and safeguards being developed. Too often safeguards restrict and limit the person with a disability in order to provide ‘protection’. They become the ‘victims’ as well as, or rather than, the exploiters or abusers - and then ‘victimised’ again, because they cannot easily remedy these imposts because of their ‘incapacity.’ This form of ‘preventative protection’ is often based on historical stereotypes about disability, is put in place to prevent an adverse event occurring in the future or after an event or harm has already occurred.

- Personalisation and Protection
  Personalisation and protection may appear to be in conflict but both are necessary for the empowerment of people with disabilities. Personalisation means letting people with disabilities make choices and take risks; decide on services, interventions and safeguards based on their own aspirations and personal preferences; and drive the necessary planning processes. It does not mean abandonment – the challenge is to find new ways of keeping them safe and preventing them from harm - without interfering with their rights.

  In Australia, the proposed NDIS, with likely associated growth in individual budgets and purchase of support from a wider range of providers (including those outside current government funding and regulation) will have obvious decision making and safeguarding implications. It is, however, these very arrangements that can provide a pathway out of or escape from overly dependent, exploitive or abusive situations. The latter includes less tangible forms of abuse such as through omissions and denial of opportunities.

- Re-focussing the Balance between Rights and Protection
  There is a big difference between having legal capacity and being able to exercise it. Access to support or assistance might be needed, which the UN CRPD creates an obligation to be provided – before any measure that interferes with any right is taken. In respect to decision making, there is a duty on others to accept a person’s decisions and their means of support in making or expressing that decision. Any measure that interferes with this or any other right needs to be proportionate to the issue, tailored to the person’s circumstances and apply for the shortest period possible; be free of conflict of interest, undue influence and potential for abuse; and (the measure) must be regularly, independently and impartially reviewed. Measures must build the capacity and resilience of the person so as to avoid their need in the future.
• Universal Protection Mechanisms

Article 16 (Freedom from violence, exploitation and abuse) and 13 (Access to justice) require that in prevention or redress of abuse, exploitation, neglect or omissions, measures taken must be gender, age and disability sensitive and provide full access to the available remedies, legal or otherwise, on the same basis as others. Conceivably, with such equal access to the same protections afforded the whole community, systems for rights enhancement can do just that; focus on rights and rights protection.

Article 16 obliges state to ‘ensure all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities’. This includes any measure that interferes with a person exercising their legal capacity, including guardianship and trusteeship services.

• A Primary Response: Early Intervention and Prevention

Many safeguards operate at a secondary level of intervention and rely on complaints being initiated - after harm has been done. Complaint processes however are not necessarily tailored to the different needs of people living with a disability. In general, practical support to make a complaint is missing and there is little attention to the factors which might prevent them from making a complaint. Primary interventions that will prevent harm occurring include education and information on rights, processes and procedures, what to expect of others, how to complain and obtain support to complain combined with proactive and regular opportunities for feedback and engagement with monitoring bodies or persons and the wider community.

These factors and considerations would suggest that some of our systems in Australia that have dual functions of protecting peoples’ rights and interests and providing ‘welfare’ responses to issues of safety and freedom from abuse - might not be the best mechanism for a strong focus on rights, legal capacity and supported decision making. Indeed where they are also a provider of guardianship services, their role in ‘independent monitoring’ of rights abuses is compromised as is their capacity to provide and maintain a primary intervention focus (due to pressure to provide guardianship or protective services).

A similar tension is illustrated in the following footnote 75 to a recent Australian report.

‘The Australian Federation of Disability Organisations (sub.DR982) argued that it would violate the UN Convention of the Rights of Persons with Disabilities were funding only to be available to people who could meet the risk criteria. However, this fails to recognise that poor risk management could easily harm the person with a disability, contrary to the goals of the UN Convention to protect their interests.’
The above illustrates that reconciling all the Articles of the UN CRPD can be difficult and also, how far away from asking the question ‘what support is needed and what accommodation do we (and others) need to make so that they can access ........... on an equal basis with others? And what safeguards do they want or need so they can do this?’

- Positive protections that facilitate a person’s rights, interests and decision making and protect these, rather than negative protections that infringe, restrict or withdraw these rights and autonomy, should be the focus of any statutory safeguarding mechanisms.

- The perception that supported decision making might expose people to more risks, or rather, that guardianship is the ultimate protection, needs to be challenged. Opportunities for potential abuses associated with guardianship and other legal instruments flourish, in both developed and undeveloped countries and existing systems.

- Safeguarding solutions should not cast the blanket of state intervention more widely. Arguably this would be a human rights violation, discriminatory and as well, impractical.

- Inclusion and social capital are the foremost protective factors for people with disability. This does not mean they should be abandoned. While ‘included’ they will need to access the universal protections afforded the whole community, on an equal basis with others, with appropriate accommodations and differentiation.
Capacity Building Strategies

Throughout this report are examples of capacity building strategies. These include, sharing information across regions/countries, bringing in fresh thinking and experts to broaden peoples’ thinking and developing training and education programs for all stakeholders, including people with disability, their service providers, social service professionals and health practitioners and the wider community.

Overseas examples demonstrate access to philanthropy, to EU and other sources of funding - the benefit of which is enormous. This supports innovation, international dialogue and a vast array of trial projects consistent with UN CRPD and Article 12. Of note, and somewhat different to the Australian experience, is

- a culture of philanthropy,
- funding of research, advocacy and academic centres devoted to the topic and to building and influencing policy, reform and sector capacity,
- development of a number of social enterprises that collaborate to provide evaluation, resource development, policy advice and standards and quality assurance,
- engagement of people with disabilities (and DPO’s), their access to information on the progress of UN CRPD and support and opportunities to reflect and comment on developments and policy options, and
- a high level of transparent, accessible consultation and discourse with government (in many cases or emerging), academic, legal, professional and peak bodies on the UN CRPD and its implementation.

In the 1980’s Australia (at the Federal level) used both legislation and funding to drive de-institutionalisation and improve community integration; with the additional benefit of public education, awareness and attitude change. During this approach, a number of ‘demonstration’ projects were funded. Many of these brought together people with disabilities, their families and community to trial new ways of meeting needs and achieving ‘normalisation’. An investment in a similar strategy to entrench legal capacity rights and Article 12 would be timely.

Avoiding or mediating polarisation on issues is a big part of capacity building. One example is the question of whether there is any place for substitute decision making in complying with UN CRPD. In an informal conversation it was said to me, ‘if I fall over, hit my head and am unconscious, I would want you to ring an ambulance and put me in it – not wait till I am conscious so you can ask me what I want to do.’ In the context of substituted decision making and involuntary treatment - this could be both. Practicality, common sense and responsible citizenship have to prevail. Just as disability should not be a basis for denying people rights nor should it be a barrier to humane actions towards them. Similarly, whether a person has a substitute or proxy decision maker should not be a polarising matter. After all, people without disabilities can appoint temporary of enduring powers of guardianship. It is whether other
options are available, have been offered and tried; the decision for such arrangements is an informed choice, salient of all other possible alternatives; and that these respect their right to choose (or end) such arrangements and honour their personal plans, will and preferences and the choices made or wanting to be made. Help to act on those choices and the reasonable accommodation of others may be required and must also be available. Involuntary substitute decision making (not a maker) should not be the norm and be considered only as the absolute last resort.

- A range of projects in areas related to Article 12, supported decision making and personal planning involving stakeholders is needed to develop appropriate options.

- It is critical that the primary stakeholders, people with disabilities, are involved in dialogue, information sharing, projects and planning to inform any new systems, as is transparency and access to information related to UN CRPD’s implementation in Australia (and elsewhere).

Challenges

Financial administration and trusteeship requires specific comment. If through an intervention or administration order, someone is prevented from controlling their own affairs, this is inconsistent with UN CRPD and Article 12 (5) which promotes equal right to property, finance and control of personal affairs. By comparison with Canada and the UK it appears that external financial administration occurs to a greater extent in Australia. (Elsewhere the issue is somewhat absorbed into the application of plenary guardianship). A person on a pension or disability allowance or adjusted wage would not come under a financial order in Canada and the UK. That is not to say they would not get support – but this might come from their benefit provider or others – their legal capacity would not be taken away. It has been suggested that the nature of a ‘trustee’ arrangement makes it difficult to build in practices based on the principles of proportionality and developing capacity.

- The use of financial administration orders/trusteeship as a first resort in Australia warrants research; firstly to understand its use and any perverse incentives or system gaps that might be encouraging it and secondly, to test what other alternatives could be provided consistent with Article 12 and supported decision making.

- Strategies (such as Canada’s RDSP) that help to build a person with disabilities financial independence in later years, consistent with opportunities afforded to other Australians would be entirely consistent with UN CRPD.
Three other challenging issues arise from the debate and implementation considerations for Article 12. These are the validity of forced or involuntary detention and treatment for people with mental illness (or psycho-social disabilities), the operation of informed consent practices and the appropriateness of the defence of mental incompetence or impairment in the criminal law. To my knowledge, there has not been much consideration or debate of these issues in Australia as a consequence of the UN CRPD.

In regard to the first, the validity of forced or involuntary detention and treatment for people with mental illness (or psycho-social disabilities) - the benefit of having a supporter at decision making for treatment cannot be underestimated.

- There is immense value in the CDLP’s emphasis on having supporters at the time of voluntary admission or treatment decisions (see page 42) and appropriate safeguards for informed consent.

- Re-consideration of the defence of mental incompetence in the criminal law is a necessary, but challenging consequence of Article 12. New Zealand’s Office for Disability Issues website suggests that legal capacity ‘can still be lost in situations that apply to everyone, such as if someone is convicted of a crime’.

Throughout my Fellowship I encountered varied viewpoints about the inclusiveness or broadening of the definition of disability, implicit in the UN CRPD. Actually, the UN CRPD does not define disability at all, whereas it is often the case that domestic legislation will define disability in terms of a medical condition, functional categories of disablement or degrees of impairment.

Article 1 of UN CRPD describes persons with disabilities as those with ‘...long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.’

Such a descriptor reflects the social construct of disability and how the barriers experienced by persons with disabilities may vary from person to person and circumstances even though they might have the same type or level of impairment. It also forces others to think about and differentiate the impact of any impairment; to not use stereotypes; and to personalise assessments, services and responses.
Other thoughts arising from my fellowship, international observations and reflection relate to the question of what might Australia learn from less developed countries. I have already mentioned various capacity building strategies, including projects, research, education and international collaboration. Other considerations for Australia are:-

Rights or Welfare:

In Australia, it could be argued that the major focus of ‘rights protection’ has been at a sophisticated, higher level and more accessible and relevant to educated, middle class segments of the population with associated, mirroring bureaucracy. Some of the rights abuses encountered daily by many less advantaged citizens are not dealt with as a matter of rights, but rather, welfare. This results in further disempowerment, dependencies, stereotypes and more rights abuses.

Barriers to more radical rights focussed reform:

Compared to many other countries, there appears to be less debate, dialogue or passion about the UN CRPD and Article 12 in Australia. Could the above dynamic and a certain comfortableness with the current (often good) systems, be a barrier to taking a fresh look at these systems with our eyes firmly on the UN CRPD and the rights it confers?

Grass roots involvement and action:

While there are a number of institutional reform projects being undertaken such as in SA and NSW, we lack the grass roots action, involvement of people with disabilities, mobilisation and innovation that needs to accompany reform. This, understandably, is more present and a strong driver of change in less developed countries. Can more be done to engage with people with disabilities and to support and encourage user–led projects? Ready access to information and its exchange on the UN CRPD, their rights and involvement in how to improve these is needed.

Government machinery and processes in Australia:

Article 33 requires state parties to the UN CRPD to have a high level focal point with relevant mechanisms at different levels of government or sectors to ensure effective coordination. Australia has a shared focal point, being the Federal Attorney-General’s Department (AGD) and Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). No doubt discussion occurs in COAG, or at the Standing Committee of Attorney-General’s (SCAG) or on other government forums – but the information is not necessarily accessible or transparent. In contrast the UK, Canada and New Zealand have their Offices of Disability Issues as the focal point, with relevant information accessible, through their websites.
6 Recommendations

The following is a summary of recommendations arising from the above conclusions and other discussion in this report.

1: Article 12, legal capacity and supported decision making arrangements reflect a human development and rights approach that needs to be echoed in all policies, practices and legislature. Enabling legislation is a vehicle for this and in SA it has already been recommended.

2: In Australia there is an emerging platform of disability policy based on rights, rights enhancement and protection and self-determination. This requires:
   2 (a) Assistance, supports and accommodation of others (if need be) for people with disability to self-determine and control their own life and affairs
   2 (b) Systemic and integrated reform across a range of policy arenas
   2 (c) Independent monitoring of the implementation of policies to ensure consistency with this goal and the outcomes achieved.

2: Article 12 is not just about guardianship, it needs to be taken in its entirety together with all the articles of the convention. Responses need to respect that decision making capacity is a normal developmental process, based on life experience and opportunities that are often compromised for people with disabilities. These opportunities need to be encouraged and facilitated, rather than denied or limited.

3: The focus of disability, capacity and other policies must be on inclusion and social capital so as to sustain and build natural, freely given relationships that will empower and support people living with disability in decision making about their own lives.

4: The absence of such relationships must not be a barrier - the focus should be on facilitating and enabling such relationship to be developed, and this could be through mechanisms that encourage circles of friends and access to voluntary supporters.

5: An investment in the varied types and spectrum of support that will assist and augment decision making is required including independent and conflict free support for making life and personal support plans.
6: Greater engagement of families and people with disabilities in dialogue on Article 12 and in the planning and projects for developing appropriate supports and safeguarding regimes – and in a variety of contexts.

7: The practice of supported decision making should not become ‘professionalised’, however, clear guidance is required on the issues, approach, support and context for both people with disabilities and their supporters.

6 (a) A source of guidance and tools, as well as access to mediation, peer support and advocacy are necessary for the successful implementation of supported decision making.

6 (b) A simple written agreement is a valuable tool as are current, advance or proxy directives.

6 (c) An independent legal capacity resource, a quality standard requiring it in disability and other policies and the onus to provide reasonable accommodations within law and policy will be powerful change levers.

6 (d) The type and nature of support required will be unique to each individual and their circumstances. Over prescribing provisions or steps could distort or even bureaucratise natural, freely given relationships.

7: Inclusion with social capital is the foremost safeguard for people with disabilities, but they still need to be protected while included. Barriers to accessing justice and universal safeguards need to be removed, including insensitivity to their needs and vulnerabilities arising from dependencies and a lack of differentiation, accommodations and support.

7 (a) The scrutiny of existing legal instruments (private guardianship and administration of affairs, Enduring Powers of Guardianship, Enduring Powers of Attorney) needs to be strengthened, so as to ensure that these and informal arrangements respect the will and preference of the person with a disability.

7 (b) Decision making safeguards are required - to protect the decision making rights of people with disabilities and to enhance their capacity for this and to act on decisions made. This should be the focus of tribunals and state interventions.
7 (b) Any intervention needs to be the absolute last resort, and even then, the assessment of the need for intervention and the measure taken should be related to the specific decision needing to be made at the time.

7 (c) Primary prevention strategies are required, including: education and information on rights, policies, processes and procedures; conflict free decision making support; community education and promotion; and independent planning for personal support and life aspirations.

8: Capacity building strategies should include community education programs, trial projects involving people with disabilities, their families and support providers, engagement with people with disabilities on Article 12, the UN CRPD and supported decision making and more information sharing.

8 (a) An independent resource organisation and structures similar to NIDUS and local structures as proposed in India would be valuable capacity building and safeguarding components for the implementation of supported decision making.

8 (b) In tandem, wider disability policy should provide for service providers to ensure supported decision making arrangements or agreements are in place. This would help take up and universalise the approach.

8 (c) Spectrums of support and initiatives should be trialled to develop supported decision making arrangements and safeguards.

8 (d) Services must be (re) oriented to the assets and developmental capacity of persons with a disability and to creating the space for trying out, innovating and mistake making that is often denied persons with a disability.

9: Alternative options for financial administration arrangements consistent with supported decision making and which, honour legal capacity need to be researched and developed.

10: Article 12 suggests that other areas of the law also need to be considered, including the operation of informed consent, the defence of mental incompetence in the criminal law and involuntary detention and treatment under mental health laws.
Appendix One
UN CRPD Article 12

Article 12 Equal Recognition before the Law

12 (1) Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

12 (2) Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

12 (3) Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

12 (4) Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

12 (5) Subject to the provisions of this article, Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.


Introduction

Article 12 accords to people with disabilities recognition equal to others as full persons before the law. To be recognized as a full person before the law means that one’s legal capacity, including the capacity to act, is equally recognized. Article 12 also imposes a positive duty on the state to establish support measures to ensure that the barriers to exercising legal capacity are removed and that the supports are in place for people with disabilities to fully enjoy and exercise this capacity. Insofar as present day national laws impose barriers to the exercise of legal capacity by persons with disabilities, or deny access to needed supports for the exercise of legal capacity, it is necessary for States in accordance with their obligation under article 4 (1) (b) to modify these laws to bring them in consonance with article 12. In order to assist States Parties in their law reform activity we have outlined the implications of article 12 below.

Overarching Principles

1. "Legal capacity" is best translated as the "capacity for rights and capacity to act".

2. "Legal capacity" for the purpose of the Convention on the Rights of Persons with Disabilities means both the capacity for rights and the capacity to act. This applies in the legal systems of all countries for all people, including those with disabilities.

3. The right to enjoy and exercise legal capacity applies equally to all people, including those with disabilities, irrespective of the nature or effects of their disability or apparent need for support. Legal capacity cannot be questioned or challenged based on disability.

4. People with disabilities who need support to exercise legal capacity have a right to be provided with such support. Support means the development of relationships and ways of working together, to make it possible for a person to express him or herself and communicate his or her wishes, under an agreement of trust and respect reflecting the person’s wishes.
5. All people who have difficulty exercising their legal capacity can be accommodated within the support paradigm.

6. All adults, including those with disabilities, have an inalienable right to exercise their legal capacity. This means they cannot be prevented from doing something that they are otherwise permitted to do in the exercise of personal autonomy. They also have the corresponding duty to fulfill their responsibilities. Support and/or reasonable accommodation may be necessary to equalize the effective enjoyment of these rights and fulfillment of duties.

7. All children, including those with disabilities, have an evolving legal capacity, which at birth, begin with full capacity for rights, and evolve into full capacity to act in adulthood. Children with disabilities have the right to have their capacity recognized to the same extent as other children of the same age, and to be provided with age- and disability-appropriate supports to exercise their evolving legal capacity.

8. Parents and guardians have the right and responsibility to act in the best interests of their children while respecting the child’s evolving legal capacity, and the state must intervene to protect the legal capacity and rights of children with disabilities if the parents do not do so, in accordance with the Convention on the Rights of the Child. The parents’ or guardians’ rights to act on behalf of their children cease when the child reaches the legal adult age. This must be the same for all persons to avoid classifying people with disabilities as children at an older age than others.

Building Legislative & Community Structures for Supported Decision Making

9. Governments are responsible for replacing existing substitute decision making laws and policies with supported decision making mechanisms that are recognized in legislation and have corresponding policies and programs to effectively implement a system of supported decision making.

10. Governments are responsible for developing, supporting, promoting and offering support services, and for establishing safeguards to ensure a high quality of support and its compliance with standards such as: respect for the rights, will and preferences of the person, freedom from conflict of interest and undue influence, and being tailored to individual circumstances.

11. Support must not restrict the rights of the person or coerce the person to act in a particular way. Support must not affect his or her capacity to act. A person cannot be made to accept support against his or her will.

12. Different types of support should be promoted and encouraged to meet the wide range of needs among people with disabilities and allow for personal choice among different
options. Types of support may include, for example, support networks, personal ombudsperson, community services, peer support, personal assistant, and advance planning. Age, gender, cultural and religious preferences, and similar factors must be taken into account, as well as needs expressed by people with different types of disabilities.

13. Interim measures may be needed when it is difficult to determine a person’s wishes and it appears that the person may need support, or when support fails despite good efforts. In such cases, skilled supporters trained in establishing proper communication and the obligation to respect autonomy should be available to help. Governments should also promote advance planning for support that people may anticipate needing in the future.

14. A person may agree with his or her supporter(s) that the supporter(s) can make certain types of decisions, should the supporter be unable to determine the person’s wishes at a particular time. This does not mean that the person loses his or her right to make those decisions. The supporter is bound to keep making the effort to communicate and to follow the person’s wishes as far as they may be known.

15. If no such authorization has been made and communication has failed despite good efforts, skilled supporters should continue trying to establish communication, while a decision is made that has the least possible effect in foreclosing opportunities for later revision.

16. Decisions that involve highly personal values and/or controversial measures that may violate a person’s physical or mental integrity such as sterilization, cochlear implants, neuroleptic drugs, electroshock and psychosurgery, should not be permitted without the informed and affirmative consent of the person concerned.

Dismantling Substitute Decision Making Systems

17. Governments must act immediately to
   a) recognize the equal rights of all persons to have and exercise legal capacity without discrimination based on disability;
   b) establish a legislative, policy and financing basis for
      I. provision of support in decision making in accordance with the principles outlined above; and
      II. the duty of all those in the public and private sectors to accommodate persons with disabilities who may require support in decision making; and
   c) abolish
      I. plenary guardianship;
      II. unlimited time-frames for exercise of guardianship;
III. the legal status of guardianship as permitting any person to override the decisions of another;

IV. any individual guardianship arrangement upon a person’s request to be released from it;

V. any substituted decision-making mechanism that overrides a person’s own will, whether it is concerned with a single decision or a long-term arrangement; and

VI. any other substituted decision-making mechanisms, unless the person does not object, and there is a concomitant requirement to establish supports in a person’s life so they can eventually exercise full legal capacity.

18. All laws and mechanisms by which a person’s capacity to act can be deprived or restricted, based on differences in capabilities, must be abolished or replaced with laws that recognize the right to enjoy and exercise legal capacity. In addition to substituted decision-making mechanisms as mentioned above, this includes declarations of incapacity, interdiction, welfare orders, commitment to institutions, and compulsory hospitalization or medical treatment.

19. Similarly, any laws disqualifying a person from enjoying rights or performing legal acts or responsibilities based on disability must be abolished. For example, voting, holding public office, serving on juries, giving or refusing free and informed consent, inheriting or owning property, marriage and raising children, are rights guaranteed in the Convention that also involve an exercise of legal capacity. Support and/or appropriate accommodation must be provided where necessary to exercise these rights and responsibilities. The signatures of people with disabilities are entitled to equal recognition as those of others.

20. In implementing Article 12, governments must address its implications for criminal responsibility and the criminal justice system. Persons with psychosocial disabilities have an equal legal capacity with others to be held responsible for wrongdoing, whether through a civil, criminal or other process, and to be provided with all needed supports and accommodations to ensure access to justice and conditions of punishment that respect human rights and dignity. The death penalty and similar harsh measures must be abolished to ensure humane treatment for all.

21. Implementation of all aspects of Article 12, including the development and provision of support, needs the active involvement and partnership of people with disabilities and the organizations they choose to represent their interests (in particular, organizations of people with disabilities controlled by themselves). All those who seek the protection of the Convention within an evolving concept of disability should be welcomed.
Appendix Three

A stepped model of supported decision making (OPA South Australia)
End Notes and References


3. An introduction and videos of sessions from this conference can be found at http://cic.arts.ubc.ca/research-knowledge-exchange/supportive-decision-making.html


9. UN CRPD Enable website Definitions http://www.un.org/disabilities/default.asp?id=262 accessed 01/12/12


14. Information on the Victorian Law Reform Inquiry into Guardianship can be found at http://www.lawreform.vic.gov.au/inquiries/guardianship. A final report has been prepared but not yet publically released as at `1/02/12


16. Information about RDSP can be found at http://rdsp.com/ accessed on 01/12/11

17. Information on the Victorian Law Reform Inquiry into Guardianship can be found at http://www.lawreform.vic.gov.au/inquiries/guardianship. A final report has been prepared but not yet publically released as at `1/02/12

18. Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. It represents over 200 member federations in 115 countries. Accessed at http://www.inclusion-international.org/ on 10-02-12


20. Information about RDSP can be found at http://rdsp.com/ accessed on 01/12/11
19 ‘Vela’ Micro-Board operates in Canada and now in some Australian states. A Micro Board is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group address the person's planning and support needs in an empowering and tailored fashion, using the person centred planning philosophy. This it is created for the sole support of one person. [http://www.microboard.org/what_is_velopro.htm](http://www.microboard.org/what_is_velopro.htm)

20 Bach, M ‘Individualized Funding and Self-determination: Making sure the means does not become the end’- First International Conference, on Self-determination and Individualized Funding, Seattle, July 30, 2000 accessed at [http://members.shaw.ca/individualizedfunding/Articles%20for%20download/Self-Determination%20-%20Michael%20Bach.doc](http://members.shaw.ca/individualizedfunding/Articles%20for%20download/Self-Determination%20-%20Michael%20Bach.doc) 01/12/11


24 A discussion paper which discusses Canada’s legal approaches, including legislative options in Ontario was tabled and presented at the “In from the Margins Conference”, BC, Canada, April 2011, entitled “Paving the way to full realization of the CRPD’s Rights to Legal Capacity and Supported Decision Making: A Canadian Perspective”. This can be accessed at [http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf](http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf)


31 Page 22, Brown (2003) at endnote 8 above


33 Silvers, A- Professor and Chair, Philosophy Department, San Francisco State University: ‘Moral status; what a bad idea’ paper presented at ‘In from the Margins’ University of British Columbia [http://cit.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/MORAL_STATUS_SCOPING_PAPER_-_Final_Antina_Silvers.pdf](http://cit.arts.ubc.ca/fileadmin/user_upload/CIC/July_2011/MORAL_STATUS_SCOPING_PAPER_-_Final_Antina_Silvers.pdf)

34 Information on this agency can be found at [http://www.isa.homeoffice.gov.uk/](http://www.isa.homeoffice.gov.uk/) accessed 01/11/11
Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities.

4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted. Accessed at http://www.un.org/disabilities/convention/conventionfull.shtml 10-02-12

45. **Article 19 - Living independently and being included in the community**

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services facilities for the general population are available on an equal basis to persons with disabilities & are responsive to their needs. [http://www.un.org/disabilities/default.asp?id=279](http://www.un.org/disabilities/default.asp?id=279) accessed 11-02-12

46. Centre for Disability Law & Policy NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defence & Equality accessed 15/12/11 at [http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf](http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf)

47. The system of a Personal Ombudsmen (PO) for psychiatric patients is a Swedish innovation. A PO is a professional, highly skilled person, who works to 100 % on the commission of the psychiatric patient only. The PO is in no alliance with psychiatry or the social services or any other authority and not with the patient’s relatives or others in his surroundings. The PO does only what his client wants him to do. As it can take a long time before a client comes to know and feels comfortable disclosing the help they want, the PO has to wait, even though a lot of things might be chaotic. This requires a commitment to long-term engagement with clients, over many years, in order to develop a trusting relationship. Accessed at [http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php](http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php) 10-02-12


49. It is acknowledge that in this section due to language barriers further information was referenced from the websites about and reports from the organisations mentioned in this discussion.

50. Over 67,000 adults with disabilities in Hungary are deprived of legal capacity. Approximately 15,000 people with intellectual disabilities and 8,000 people with psycho-social (mental health) disabilities live in large residential institutions. According to the 2001 figures, there were 577,000 people with disabilities, constituting 5.7% of the population. (In 2011 the population of Hungary was reported to be approximately 10,000,000). There are huge inequalities between different parts of the country; 68% of persons with disabilities live in villages or small towns. Persons with physical disabilities represent 43.6%, persons with mental disabilities 10%, and the blind and partially sighted 14.4%. The rate of other disabilities is 21.6%. Further about 10% of all persons with disabilities have hearing impairment or a speech-related disability. Source 'Disabling Rights: CRPD Alternative Report’. Prepared by the Hungarian Disability Caucus Published by SI NOSZ, MDAC an d FES ZT August, 2010 Accessed at [http://mdac.info/sites/mdac.info/files/english_crpd_alternative_report.pdf](http://mdac.info/sites/mdac.info/files/english_crpd_alternative_report.pdf) 12-02-12

51. ‘The Mental Disability Advocacy Centre (MDAC) is an international human rights organisation which advances the rights of children and adults with intellectual disabilities and psycho-social disabilities. MDAC uses law to promote equality and social inclusion through strategic litigation, advocacy, research and monitoring and capacity-building. MDAC operates at the global level as well as regional and domestic levels in Europe and Africa. MDAC is headquartered in Budapest, Hungary and was registered as a foundation by the Budapest Capital Court (registration number 8689) in November 2002. The Open Society Foundations (OSF) founded MDAC and continues to be one of its donors. MDAC has participatory status with the Council of Europe. In 2011 MDAC was granted a special consultative status with the United Nations Economic and Social Council.’ Information from MDAC website [http://mdac.info/](http://mdac.info/) accessed 01/11/11 ‘MDAC’s work in Hungary is supported by a grant from the EEA/EFTA Financial Mechanism, the Hungarian Environmental Partnership Foundation and its partners. The work is also supported by a grant from the Trust for Civil Society in Central and Eastern Europe.’

52. Legal Capacity – Creating a New Civil Code in Hungary accessed at [http://mdac.info/content/legal-capacity-%e2%80%93-creating-new-civil-code-hungary](http://mdac.info/content/legal-capacity-%e2%80%93-creating-new-civil-code-hungary) 11/10/11
53 As in the Hungary section of this report, it is acknowledged that in this section due to language barriers further information was referenced from websites about and reports from the organisations mentioned in this discussion.

54 The 2007 ‘Czech Bureau of Statistics, Sample Survey of people with disabilities in the Czech Republic’ estimates a population of 1,015,548 disabled persons from a total population of 10,287,189 (52% women and 48% men, but in every age category up to the age of 74 the number of men with disabilities slightly predominates over the number of women). Of this population: 46,208 are aged under 14; 407,695 are aged 15-59; 560,018 are aged 60 and over. Source Academic Network of European Disability experts (ANED) – VT/2007/005 http://www.disability-europe.net/content/aned/media/Czech%20Republic%20ANED%20country%20profile.pdf Accessed 10-02-12

21,000 people live in Institutional care –mostly publicly administrated and within regional councils. Institutional capacities range from 25 to approximately 250. Community social services users are about 1700 for personal assistance, 839 for supported housing and 608 for early care. Guardianship - more than 25,000 adults with disabilities are under guardianship Source Information provided by Quip


56 Information about QUIP can be found at http://www.kvalitavpraxi.cz/en/about-us.html accessed 10/02/12

57 Ibid

58 India estimates that 100 million people have disabilities http://infochangeindia.org/disabilities/backgrounder/disabilities-background-perspective.html, which is nearly 1/ 6th of the estimated 650 million people with disabilities in the world. http://www.un.org/disabilities/convention/facts.shtml. 50% of their current population (approx. 1.22 billion) are aged below 25 years of age and 65% below 35 years. Approximately 70% live in villages and non-urban areas.

59 Available at http://socialjustice.nic.in/pdf/draftbill-pwd.pdf

60 Available at http://www.disabilityindia.org/pwdacts.cfm

61 The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 accessed 10/02/12 http://thenationaltrust.in/yahoo_site_admin/assets/docs/NT_Act_1999_96125125.pdf

62 As discerned from meeting with J.P. Gadkari, Director Projects and Development, PARIVAAR and PARIVAAR Newsletters of Jan-Mar 2001 Edition Vol.x11 No.1 and April- Sep 2010. Vol. X1 No 2-3 (provided by Mr Gadkari)

63 See footnote 62 for Information on PARIVAAR

64 PARIVAAR - NATIONAL CONFEDERATION OF PARENTS ORGANIZATIONS (NCPO) was formed in the year 1995. It is a Federation of over 150 Parents Associations and NGOs in 27 States of India working for people with Mental Retardation, Autism, Cerebral Palsy and Multiple Disabilities. PARIVAAR is a grass - root level organization with 70 urban, 42 semi-urban and 38 rural parents associations. http://parivaarnfpa.org/ For information about SDM projects see http://parivaarnfpa.org/uncrdp.php


66 Ibid pages 17 – 23, Professor Henare is Associate Dean, Māori & Pacific Development, University of Auckland Business School, New Zealand

67 ‘He Ara Hou: The Pathway Forward Getting it right for Aotearoa New Zealand’s Māori and Pasifika children’- This report was commissioned by Every Child Counts and led by Manuka Henare, Adrienne Puckey, and Amber Nicholson Mira Szászy Research Centre, the University of Auckland. Analysis by M. Claire Dale and Rhema Vaithianathan - Centre for Applied Research in Economics (CARE), University of Auckland. August 2011 accessed at http://img.scoop.co.nz/media/pdfs/1109/He_Ara_Hou_Report_2011_FINAL.pdf 16-02-12

69 Dhanda, A “Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?”, reported in the Centre for Disability Law & Policy NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defence and Equality

70 Discussion of this is throughout the Centre for Disability Law & Policy NUI Galway Submission on Legal Capacity the Oireachtas Committee on Justice, Defence & Equality accessed 15/12/11 at http://www.nuigalway.ie/cdlp/documents/cdlp_submission_on_legal_capacity_the_oireachtas_committee_on_justice_defence_and_equality_.pdf


72 Ibid, page 19


76 Refer to CDLP report Centre for Disability Law & Policy NUI Galway Submission to the Department of Health on its Review of the Mental Health Act 2001 accessed 18-02-12 http://www.nuigalway.ie/cdlp/documents/cdlp_mental_health_act_2001_submission.pdf