

*Rights for
Persons with
Cognitive
Disabilities*

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TRUST

Supported Decision-making: Learning from Australia

Jan Killeen
Winston Churchill Memorial Trust
Travel Fellowship 2016



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Acknowledgements

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*Typical Victorian farm barn
that's seen better days.*

Preface: About me

Much of my working life has focused on advancing the legal and civil rights of people living with dementia and others with cognitive disabilities. My Churchill Fellowship has enabled me to build on that work. In 1981 I moved from England to Scotland with my family and was employed by Age Concern Scotland as a training officer where I organized the first major conference on dementia in 1984. The response from carers and professionals alike was overwhelming and led to the establishment of the charity, 'Scottish Action on Dementia' (SAD). Collaboration for change is central to the way I work and I have been privileged to engage with experts from across the disciplines, who are similarly dedicated to advancing the sorely neglected rights of people with cognitive disabilities. In 1994 SAD and Alzheimer Scotland merged to become Alzheimer Scotland – Action on Dementia with myself as Policy Director. Human rights issues continued to underpin all our work and I coordinated a national campaign for law reforms leading to the introduction of the Adults with Incapacity (Scotland) Act 2000; then commissioned by the Scottish Government to lead research into its effectiveness and make recommendations, which in turn led to my being seconded to coordinate an action programme to improve policy and practice.

On returning to Alzheimer Scotland I co-authored the Charter of Rights for People with Dementia and their Carers, and with funding from the Nuffield Foundation, investigated the decision-making support needs of carers with powers of attorney and guardianship, publishing a good practice guide and a report setting out recommendations for policy. Since 'retiring' in 2012, I have enjoyed working in a voluntary capacity with Alzheimer Disease International as a trainer and consultant in South India and Ghana. More recently I was sad to leave the Board of the Mental Welfare Commission, Scotland, where I served for four years as a part time Commissioner, followed by four years as a Board member. However, I am pleased to have maintained my close contact with the Commission and other colleagues through the opportunity offered by WCMT, which puts me in an excellent position to use my efforts, energies and newfound knowledge to good use.

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1. Executive summary

Introduction

This report explores the learning from pilot programmes in Australia designed to support the fundamental right of adults with cognitive disabilities to make their own decisions as far as possible. It was one of the first countries to ratify the United Nations Convention of Rights for Persons with Disabilities (UNCRPD 2008) and to examine how its laws and policies might be realigned in order to comply with UNCRPD principles. The UK government signed the Convention shortly after. Convention Article 12 (3) and (4) requires States Parties to provide access to support for people with decision making difficulties and protection from abuse of those rights. Australia has become a world leader in developing research programmes to find effective ways of providing support for people with decision-making difficulties and the search continues in this complicated area of human rights.

The objective of this project is to identify the knowledge, skills and methods of delivering decision-making support that is transferable to the UK. In so doing the intention is to influence law and practice to improve the lives of people with cognitive disabilities and to highlight areas for collaboration for future initiatives and research.

United Nations Convention on the Rights of Persons with Disabilities Art. 12: Equal recognition before the law

'Respect for the full range of rights, will and preferences of everyone must lie at the heart of every legal regime. That must be achieved regardless of the existence and nature of any disabilities'

'States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'

'States 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.'

<http://www.agac.org.au/conference-papers/94-2016-conference-papers>



My six week Churchill Fellowship visit offered a unique opportunity to gather information about good practice emerging from the supported decision-making pilots and gain insight into issues and challenges arising for researchers, policy makers, service providers, professionals, families and communities. The annual national conference of the Australian Guardianship and Administration Council (AGAC) 'Reflecting on Will and Preference in Decision Making' gave me an overview of the range and depth of work in progress, the opportunity to make a number of valuable contacts and to present my own work on dementia and decision-making.

In addition, I participated in topic focused roundtable discussions and stakeholder meetings. Whilst this report cannot do justice to the ethical, philosophical and sociological discourse, it highlights some of the key issues raised (see section 6).

Bigby, C., Douglas, J., Carney, T., Then, S., Wiese, I., Smith, E. (in review) Delivering decision making support to people with cognitive disability – what has been learned from pilot programmes in Australia from 2010 – 2015.

I was fortunate to have access to the findings from a critical review of the evaluations of six supported decision making (SDM) models piloted between 2010 – 2015 which provided evidence based information on outcomes for participants (people with a cognitive disability and their supporters). (See section 4).

It was important for me to experience support for decision-making in action and my visits to six projects gave me insight into the benefits to people with cognitive disabilities and their supporters. (See section 5).

The findings in this report represent a 'snapshot' in time. It recognizes and aims to contribute to the growing body of work and action to advance Convention Art.12 rights in the UK and elsewhere. The forthcoming review of the UK government's compliance with the UNCRPD, by the Convention's Committee is welcomed as a potential catalyst for change.

Aims and objectives

This project aims to identify the knowledge, skills and methods for delivering decision-making support that is transferable to the UK. In so doing the intention is to influence practice to improve the lives of people with cognitive disabilities and to highlight areas for further research.

The term 'cognitive disability' is a generic term, which includes people with a learning disability (intellectual disability in Australian terminology), severe traumatic acquired brain injury (ABI), severe and enduring mental ill health, and dementia. The terms 'people with decision-making difficulties' and 'people with cognitive disabilities' are used interchangeably.

People with cognitive disabilities have the same civic and legal rights as everyone else but face the challenges posed not only by their disability, but by barriers in society: stigma, paternalistic attitudes and inflexible, discriminatory systems. Together with a mainly continuing medico/legal approach to mental capacity, these factors pose limitations on opportunities and choices open to individuals and can damage a person's sense of self-worth, identity and confidence.

Whilst focusing on good practice in providing support for decision-making, this project examines the policy drivers which have enabled supported decision-making initiatives to flourish in Australia and whether similar drivers exist in the UK.

Practice objectives

- Use existing and new platforms to raise awareness and contribute to creating a common understanding of support for decision-making.
- To draw attention to the education and support needs of families and other informal supporters, with special reference to those appointed with substitute decision-making powers.
- Inform professional practice.
- Contribute to review of good practice guides and other resources.
- Contribute to support for research funding applications.
- Influence UK and devolved governments to invest in supported decision-making demonstration sites, linking to recently updated mental health, dementia and learning disability strategies.

Policy objectives

Influence reforms to Adults with Incapacity (Scotland) Act 2000 and Mental Capacity Act 2005 England/Wales, mental health and adult protection laws to achieve closer compliance with Art 12.

Summary: Key Findings

1. Evaluations of supported decision-making pilots evidenced positive outcomes for decision-makers and supporters, providing the basis for a recently published 'Supported Decision-making – A Practice Framework' and new research project: 'Effective delivery of SDM' .
2. Building the knowledge and skills of family members/friends (natural supporters) is one of the most effective ways to support and sustain the decision-making ability of the person with disability.
3. Support was found to be most effective where decision makers and supporters were offered peer workshops, one to one mentoring and printed information. One to one mentoring was highly valued by supporters.
4. The delivery of SDM in partnership with independent advocacy services adds value and suggests a potential route for development in UK.
5. Supported Decision-making needs to be culturally sensitive.
6. The decision-making capacity of adults with severe and complex intellectual impairments is capable of growth through the practice of Person Centred Active Support.
7. The National Disability Insurance Service is the main mechanism for the provision of supported decision-making programmes and has parallels with Self-Directed Support in the UK. There is little evidence of outcomes from SDM programmes associated with NDIS delivery.
8. A review of evaluations of SDM pilots exposed flaws in the methodology and identified gaps in research. Supported Decision-making continues to be 'work in progress.'
9. The Australian Law Commission Report (ALRC), 'Equalities, Disability and Capacity' (2014) proposes radical reforms to guardianship laws i.e. creating a provision for the appointments of a decision-maker 'Supporter' and 'Representative'.
10. Convention Art.12 (4) safeguarding issues have received poor attention and need to be addressed as a matter of priority for policy, research and evaluations.

Summary: Key Recommendations

This report proposes that existing mechanisms and structures in the UK have the potential to adapt to ensure the right to support for decision-making becomes integral to the delivery of services; and identifies opportunities to develop and evaluate demonstration projects, which build on the learning from research and evaluations in Australia.

UK and devolved governments each to be encouraged to:

1. Convene a stakeholder group with a remit to consider how existing mechanisms and other approaches might be considered to provide SDM for people cognitive disabilities and their supporters.

2. Ensure that the design and implementation of SDM policies and implementation involve people with decision-making difficulties and their supporters.
3. Reform capacity/incapacity and mental health laws to comply with UNCRPD Art.12 (3) (4).
4. Develop a National Framework for SDM Practice.
5. Pilot collaborative education and support programmes for non-professional guardians and attorneys on how to implement principles within capacity/incapacity laws.
6. Fund research on supported decision-making pilot programs in collaboration with research institutes in Australia, giving priority to targeting people with learning disabilities and dementia as the largest groups vulnerable to guardianship.
7. Public services to Include supported decision-making principles and skills within equalities training, especially health, social care and legal professionals including the judiciary.
8. Specialist voluntary sector agencies and human rights advocates to model best practice in support for decision-making and raise awareness of Art.12 (3) (4).

2. Support for Decision-making

'Decision-making is regarded as a skill that we all learn and so is supporting someone to decide'. Fiona May, ADACAS

About decision making

How decisions are made is complex and unique to each individual. We are all influenced by a multitude of factors including culture, values, past experience, social and economic circumstances. It is normal to seek the views and opinions of friends and family about everyday and bigger decisions. Sometimes we turn to experts for advice on important decisions about our health care, finances, relationships, or where to live.

Some people with cognitive disabilities will face additional challenges in making decisions about their own lives and may need support to make decisions for themselves. A person's decision-making ability may be affected by the nature of their condition, ability to communicate, previous decision-making experience and the complexity of decision/s to be made. Other barriers may include a lack of assistance in decision-making or the belief of others that they are not capable of making decisions for themselves.

Decision-making capacity is the ability to:

- understand information relevant to the decision or action,
- to be able to weigh up the options, and
- understand the possible consequences of taking or not taking a particular decision or course of action.

Research has shown how decision-making ability can be affected by a person's emotional state: anxiety, sense of insecurity, tiredness, pain or by distractions in the physical and social environment.

H. Brown and L. Marchant (2011) Best Interest Decision-making in complex Cases: report of a study commissioned by the Office of the Public Guardian.

These factors can impact on performance particularly with regard to making bigger decisions. Without support from someone who knows the person well, any one of these factors may mask their actual decision-making capacity and could lead to a capacity assessment resulting in the unnecessary appointment of a substitute decision-maker.

About support for decision-making (SDM)

Mental capacity refers to the decision-making skills of a person. Support for decision-making (SDM) is the term generally used to describe the process of assisting a person with cognitive disability to build their capacity to make decisions for themselves. A fundamental principle of supported decision-making is that it must be person-centred, with the type and level of support tailored to each individual.

Legal capacity is the ability to hold rights and to make decisions that are respected and capable of being enforced under the law (e.g. signing contracts and agreeing to medical care and treatment). In law, capacity must be assumed unless there is strong evidence to the contrary (making foolish or unwise decisions is not to be regarded as evidence that capacity is lacking).

The Convention's Committee, General Comment No. 1 (2014) clarifies that:

'legal capacity is an inherent right, and as such is 'the key to meaningful participation in society.'

http://www.opa.sa.gov.au/resources/supported_decision_making

The South Australian Office of the Public Guardian developed the first Supported Decision Making pilot in response to UNCRPD Art .12. Other States and Territories have followed with pilot programmes targeted to people with different sources of impairment and in different social circumstances. The projects are designed to develop the decision-making ability of adults with cognitive impairment and develop the knowledge and skills of their chosen supporter/s (usually family member/s or friend) to provide effective decision-making support.

A key finding from the first pilot was the recognition that changes in attitudes and practices in the community also needed to be addressed if the person with disability was to be treated as an equal citizen. The Public Guardian proposed a 'Stepped Model of Supported and Substitute Decision-making' which clarifies the difference between 'assisted decision-making' and 'supported decision-making':

- Assistance can be provided by anyone involved in a transaction with a person with disability, for example, a health or social care worker, bank official, shop assistant etc. This may mean allowing more time for communication – to give information, explain options and for the person to determine what they want to do. (UNCRPD Art.5 requires services to make reasonable adjustments).
- Supported decision-making occurs when a person with cognitive disability asks someone they have chosen to support their decision-making, for example, to attend meetings, communicate decisions and perform other tasks associated with decision-making.
- Substitute-decision making occurs when a court/tribunal appoint a person/s to make decisions on behalf of an adult with cognitive disability who has been assessed as lacking capacity to make a decision or decisions in their own interests.

The right to decision-making support

UNCRPD states that everyone with a disability should enjoy 'legal capacity on an equal basis with others in all aspects of life'. For that to happen, they need support – either to help them make a decision for themselves or, if that is genuinely not possible, to ensure that a decision is made on their behalf, which respects their rights and gives the best 'interpretation' of what their will and preference might be. Support for decision-making is integral to accessing all other Convention rights. Art.12 (4) is about the right to protection from abuse i.e. undue pressure and conflict of interests.

The UNCRPD monitoring Committee, in its General Comment No.1 clarifies the ways in which legal capacity of a person with disability may be supported to make their own decisions, stating that there is a potential range of support available including formal and informal support arrangements of varying types and intensity. General Comment No.1 provides the following examples of what this might include:

- one or more trusted persons, peer support and advocacy (including self advocacy),
- assistance with communication as appropriate to the needs of the individual... especially for those who use non-verbal forms of communication to express their will and preferences.
- Advance Care planning – an important form of support which allows a person to state their will and preferences that should be followed at a time when they are unable to communicate their wishes to others. Comment No.1 also states that if the person so wishes, support should be provided to a person to complete an advance planning process,
- communities and the support that can be gained from these,
- special support in legal and administrative proceedings.

"The state has an absolute and immediate duty to provide access to support in the exercise of legal capacity for persons with disabilities"

UNCRPD General Comment No1.

Power me up!



3. Policy Context in Australia and UK

Australia is a federal system of government, where most of the authority to make laws and deliver services is located at the States and Territories level (with the national government responsible for social security and the recently introduced National Disability Insurance Scheme (NDIS)). Laws about guardianship, powers of attorney and supported decision-making are mainly a State prerogative and have a diversity of approaches (which is also the case in USA and Canada). The UK has three judicial systems i.e. England/Wales, Scotland and N. Ireland.

Despite this complexity, in Australia and the UK there are clearly discernible parallel drivers influencing the need for the development of a systematic approach to support for decision-making in compliance with Convention Art.12. In summary these are:

- The introduction of personalized welfare services to give control to individuals to make their own choices about how they want their support needs met. In Australia the National Disability Insurance Agency is responsible for delivering the NDIS program, which was introduced in 2013, with roll out being completed by June 2019. The government recognized that some people with disabilities would need support to use the system effectively and funds statutory and non-statutory bodies to employ supported decision-maker trainers and facilitators. In the UK, Self Directed Support legislation (2013) was implemented in 2014 on the basis of the same philosophy but without the provision of support for decision-making needed by some individual to improve access the service.
- Guardianship monitoring bodies in each country have raised concerns about the recent rapid rise in the number of guardianship orders, identifying several causes including: a perverse consequence of the above schemes having too high a test of capacity, necessitating the appointment of a guardian; risk averse policies of public and private services; under-resourcing of services and courts leading to 'short cuts' in dealing with applications and 'rubber-stamping'.
- Indications that many guardians/trustees/deputies/attorneys are ignorant of the statutory principles they must implement.
- Major capacity/incapacity law reform reviews are underway in both countries.
- UNCRPD monitoring Committee review of compliance by States Parties.

*Mental Welfare Commission
AWI Act Monitoring
2015/15*

www.mwscot.org.uk/



*'The plea'
Sculpture Assemblage
J Whittaker.*

Whilst the above drivers in civil society and governments at both federal and state level in Australia have led to the development of Supported Decision Making pilots over the past seven years, there have been no similar initiatives in the UK. However, in the UK, it is encouraging that a new disability rights agenda is emerging with opportunities to progress implementation of Art.12.

Objectives of SDM projects

The main objectives adopted by SDM projects in Australia were framed by the Office of the Public Advocate, South Australia for the first trial, which commenced in 2010:

- Advance the implementation of Convention Art.12.
- Provide assistance to individuals to make large and small decisions about their own lives as far as possible.
- Provide assistance to individuals to be as involved as possible in making bigger decisions about their health, life-style, accommodation and money.
- Build the capacity of an individual to engage fully with social welfare systems, which aim to empower people with disabilities to decide for themselves the support they want i.e. National Disability Insurance Scheme.
- Develop resources to assist people who may provide decision-making support.
- Develop SDM options as potential alternative to guardianship.
- Promote SDM practice within guardianship so that the use of substitute decision-making is limited where possible.

Law Reform

Motivated to comply with Art. 12 rights, several States and ACT have led the field by introducing law reforms, including: South Australia's legislation on Advance Care Directives (2013); Victoria's , Powers of Attorney Act (2014), making provision for the appointment of a 'supportive attorney' that is, a decision-maker supporter with powers to access data but no power to make decisions for a person with cognitive disabilities. (However, it should be noted that the term 'supportive attorney' has led to much confusion with that of Enduring Attorney and is likely to be changed). Victoria's and ACT mental health legislation also encourages the nomination of a supporter.

The Australian Law Reform Commission (ALRC) was remitted to conduct a review of the equal recognition before the law and legal capacity for people with disabilities. The outcome was the ALRC's landmark Report No. 124 (2014) 'Equality, Disability and Capacity' which provided the focus of much discussion during my visit. President, Professor Rosalind Croucher, presented her recommendations at the AGAC conference referred to earlier. Her paper: 'Towards a paradigm shift' to achieving decision-making rights for people with cognitive disabilities, summarised proposals for radical reforms which put the rights, will and preferences of people with cognitive impairments at its core, and sets out a new framework and principles for supportive decision-making.

*Office of the Public
Guardian, Victoria,
Supportive Attorney
Appointments*

<http://www.publicadvocate.vic.gov.au>

The Report advocates a new “Commonwealth decision-making model that proposes ‘supporters’ and ‘representatives’ for people with disabilities rather than substituted decision making”. The report evidences the overuse of guardianship and highlights abuse of vulnerable adults. The proposals are designed to achieve a ‘paradigm shift’ towards closer compliance with UNCRPD Article 12 (3) and (4) and the Committee’s General Comment No.1 which considers substitute decision-making laws should be abolished:

Summarised briefly in Carney T., Supported Decision-making in Australia; meeting the challenge of moving from capacity to capacity-building? (2017) 35(2) Law in Context forthcoming. The full paper is available at: <http://www.agac.org.au/images/stories/2016nsw/croucher-mod-sup-dec-mak-doc.pdf>

‘The ‘Supporter’ is someone who would have no power to make decisions but would be able to access information needed to assist the person to weigh up options and make decisions; and to provide information to others involved with the health, welfare or finances of the person.

A ‘Representative’ (the new name for someone with substitute decision-making powers) would only be appointed in cases where the individual is unable to express their will and preferences and a decision needs to be made in terms of making the ‘best interpretation’ of what the person would have chosen for themselves if able.’

The ALRC Report recommended that Commonwealth, State and Territory laws adhere to four main principles for decision-making:

- The equal right to make decisions.
- The provision of support in decision-making to the level necessary to enable them to participate in decisions which affect their lives.
- That decisions be directed by the individual’s will preferences and rights.
- That the legal framework provides protection against abuse and undue influence.

The Australian government is due to respond by 2017. If the above proposals are introduced, the provision of supported decision-making would be applicable to all age groups. Adults aged 65+ are at highest risk of dementia, and the largest group subject to guardianship. Yet, none of the SDM pilots have included this population and their supporters. It is important that new trials are funded which focus on this group. Monitoring reports from Offices of the Public Guardian across the UK and Australia indicate an over-use of guardianship for this age group. It is vital to guard against ageism within the disability rights agenda.

ALRC has recently released its ‘Elder Abuse - Discussion Paper (Dec.2016) and is soon to provide its final report. The inquiry found extensive misuse of powers of attorney and financial abuse by family members and others. The Discussion Paper sets out key proposals to increase safeguards against abuse, including additional powers of investigation for State and Territory public advocates and public guardians in relation to enduring powers of attorney and guardianship; family agreements, banking, aged care and social security.

Whilst the UK has a raft of legal protections within its capacity/incapacity /adult protection and mental health laws, nonetheless, the Public Guardian (England/ Wales) has reported increasing evidence of abuse of powers of attorney. If a new provision is to be made for the appointment of a ‘supporter’ it will be necessary ensure appropriate safeguards are in place. The provision of education and support can be viewed as part of the safeguarding package. Although it would not be possible to make participation mandatory, it would promote good practice, help to avoid unintentional abuse and raise awareness in the community.

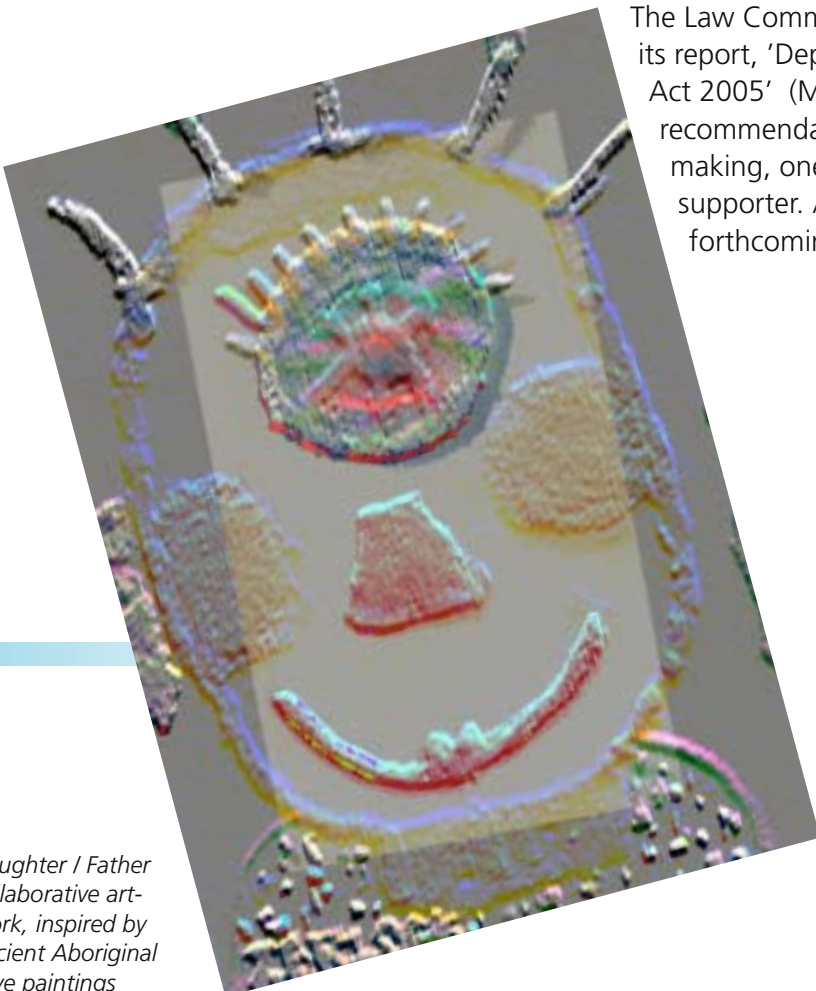
Similarly, in the UK there is considerable concern that the implementation of capacity/incapacity laws fall short of compliance with human rights principles particularly with regard to deprivation liberty and support for decision-making.

The collaborative 'Essex Autonomy Project' team instigated the 'Three Jurisdictions Project' to conduct a rigorous assessment of capacity/adult incapacity legislation in three legal jurisdictions of the UK (England & Wales, Scotland and Northern Ireland) with a view to providing the 'technical research support to UK officials who will be involved in the forthcoming UN review of UK compliance with the UNCRPD' (summer 2017).

The findings were published in the 'Three Jurisdictions Report' (June 2016). The report concluded that the Mental Capacity Act, England/ Wales, 2005,(MAC) and Adults with Incapacity (Scotland) Act 2000 (AWIA) were, 'remediable but not compliant' with Art. 12 (3) and (4). The Mental Capacity Act (NI) makes provisions for the appointment of a 'support for the decision maker' but implementation of the Act is some way off'. The report makes 10 key recommendations which reflect the principles within Article 12 (3) and (4) and suggest practical ways forward.

In response to the Scottish Law Commission's review and subsequent Scottish government's consultation on the Adults with Incapacity (Scotland) Act 2000, the Mental Welfare Commission and Office of the Public Guardian have proposed a system of graded guardianship, with provision at level one for the appointment of a decision-maker 'supporter' (report launch on 30 May 2017). The Scottish Government intends to consult on proposed reforms later this year.

The Law Commission (England & Wales) recently published its report, 'Deprivation of Liberty and the Mental Capacity Act 2005' (March 2017), which includes three key recommendations for improving support for decision-making, one of which is the appointment of a supporter. A response from the UK government is forthcoming.



Daughter / Father collaborative art-work, inspired by ancient Aboriginal cave paintings

4. Supported Decision-making Models: Key Findings

Putting the principles of self-determination into practice for people with cognitive disability is a complex process and measuring the impact of SDM interventions on outcomes for individuals has presented a research challenge. The forthcoming publication of a critical review of evaluations of six Australian decision-making support pilots, operating between 2010 and 2015, offers the best available empirical evidence of what constitutes effective practice for both the decision maker and supporter.

I visited and spent some time with members of the research team and with the staff responsible for operating the pilots. The pilots were small scale, conducted over periods of 1 to 2 years in South Australia (SA) the Australian Capital Territory (ACT) New South Wales (NSW), Victoria, and Western Australia, with collaboration between statutory and non-statutory bodies.

This section aims to highlight key features of practice, which have indicated positive outcomes for decision-makers and their supporters and areas for further research.

Overview of findings from the critical review of evaluations of Supported Decision-making models.

Aims.

The overarching aim of the pilot programs was to promote the concept of support for decision-making and enabling people with cognitive disability to have more control over their own decisions through the provision of good support.

Pilot programs aimed to:

- Learn about how supported decision-making relationships work.
- Produce information and educational resources for SDM supporters, decision-makers, health and social care professionals.
- Identify what issues might need to be considered for the broader application of a decision-making framework.
- Raise awareness of the wider community and service systems to understand equalities issues and the right of individuals with cognitive impairment to decision-making support; to increase social inclusion.

Participant decision-makers in the pilots were mainly adults with mild to moderate learning disabilities and those with acquired brain injury.

Focus of SDM models:

- Access to NDIS funding to enable people with cognitive disabilities to exercise their will and preferences as to how they want their needs to be met.
- Financial management orientation - providing training for decision-makers on how to manage their money – aiming to support the use of NDIS and divert away from Trusteeship.
- Isolated vulnerable people - pilots using trained volunteers to support people with no natural supporters to use NDIS, and for some, offering a possible alternative to guardianship.
- Building decision-support skills of supporter (usually family members or friends in a long-term relationship with the decision-maker).

Bigby, C., Douglas, J., Carney, T., Then, S., Wiesel, I., Smith, E. (in review) Delivering decision making support to people with cognitive disability – what has been learned from pilot programmes in Australia from 2010 – 2015.

A new SDM research project focusing on access to justice issues, led by Dr. Piers Gooding, Social Equality Institute, Law School, Melbourne University, aims to trial ways the support system may be improved to prevent disability-based discrimination in the criminal justice system.

Models were commonly designed on the basis of support for a decision-maker (person with disability) /supporter dyad, provided by a professional 'facilitator'. All projects employed a coordinator who recruited, trained and mentored facilitators. The roles of specialist trainers and facilitators are integral to delivering SDM and there is a growing workforce to support the implementation of new legislation which include a duty to comply with Art 12.

Either or both dyad members received training to:

- understand decision-making rights;
- build the decision-making ability of the person with cognitive disability;
- develop the knowledge and skills of the supporter to provide ongoing support to the decision-maker.

All pilots developed educational and information materials including workbooks for decision makers and supporters on decision-making.

Ongoing support was usually offered to either or both members of the dyad by the facilitator. Decision-making supporters were generally family members or volunteers (where there was no natural supporter). Other supporters were in a paid relationship to the decision-maker such as service staff, advocates or the project coordinator.

Supporters were expected to:

- Respect the rights of people with disabilities.
- Have a trusting relationship with the decision-maker.
- Accept the of values and goals of the decision maker even if they were different from their own.
- Have time to provide support.

Outcomes

"The pilots demonstrated feasibility of providing support for decision making rather than resolving issues involved in delivering support"

Whilst the review identified flaws in the quality of the evaluations, it concluded that the pilot programs "demonstrated feasibility in providing support for decision-making rather than resolving issues in delivering support".

On the effectiveness of supports offered by the pilots, evaluations highlighted the weight placed by supporters on expert one-to-one support along with small workshops. Written information alone was not found to be effective.

The following factors were found to contribute to a positive relationship between the decision-maker and their supporter, enabling the decision-maker to express and act on their will and preferences:

- the decision-maker chose the person they wanted as their supporter;
- the supporter knew the decision-maker well;
- the supporter understood SDM principles;
- the supporter took a positive approach to risk;
- the supporters had positive expectations about what the decision-maker could achieve with support, going beyond the exercise of choice to the actual implementation of decision;
- the supporter had time to provide support;
- the supporter had skills to identify formal sources of assistance and informal supports in the community to help the individual to achieve their goals.

Positive outcomes for decision-makers:

- increased confidence in decision-making – which for some extended beyond the specific decisions/goal chosen;
- greater experience in decision-making;
- increased autonomy;
- participation in a wider range of activities.

What are the outcomes for supporters?

Formal and informal supporters reported:

- satisfaction from increased autonomy of the person they supported;
- changes in work practices to encourage autonomy i.e. to engage the person in building up their experience of making choices;
- offering the individual more choices in day to day life;
- revocation of guardianship in one case;
- increased involvement of a guardian – demonstrated the feasibility of including people under guardianship as participants in SDM projects.

Barriers to effective support

Evaluations explored the barriers and challenges facing supporters and found that they were often hampered by the lack of legal authority to access essential information to help the decision-maker weigh up options and arrive at choices. This affected their ability to make financial, health, social care, accommodation or life style decisions.

Formal recognition for supporters

Findings suggested that some form of authority might facilitate the role of decision supporter. Recognition of the supporter role by public and private agencies is crucial to their ability to provide effective support. It was also felt that formal recognition would help the supporter to approach others to become engaged in the person's life, and to be better able to coordinate support. This finding supports the recommendation in the ALRC Report (2014), and proposals for the provision of an appointment of a supporter within capacity/incapacity laws in Scotland, England/Wales.

Gaps in research

- SDM models have excluded the participation of people with dementia, the largest group in society with cognitive disabilities and the most vulnerable to substitute decision-making. Other excluded groups include people with complex psychosocial conditions and 'hard cases' i.e. adults with very limited communication skills.
- Little is known about how the one-to-one mentoring relationship works between facilitators and decision-making supporters in building the capacity of individuals with cognitive disabilities.
- Lack of evaluation of the logistics of different SDM service delivery systems and their effectiveness.
- A lack of focus on safeguarding and accountability in SDM projects and research has been identified as a major concern.

The critical review of evaluations concluded that:

'We know too little about what programmes may contribute to developing the capacity of supporters and thus the social capital of the person being supported and too little work has gone into devising effective safeguards against deviation from the ideal'.

SDM training and research developments.

'Support for decision-making – A Practice Framework'

The La Trobe University research team used the findings from the six pilots and other qualitative research to inform the development of a practice framework for the provision of effective decision-making support. This is the outcome of the second phase of the Australian Research Council Linkage Grant Funding.

The framework focuses on actual practice of SDM regardless of legal context for people with cognitive disability. It describes a 'process of support' encompassing SDM principles and seven steps in support for decision-making within a strategic approach to involving the support of others.

The model extends outwards from the decision-maker/supporter dyad to building capacity through the development of connections with the person's wider community (social assets). The Practice Framework was presented at the AGAC Conference in Sydney and later at the Roundtable held at La Trobe University. The publication is going to print at the time of writing.

'Effective decision making support for people with Cognitive Disability' Phase 3: Australian Research Council Linkage Grant Funding. Living with Disability Research Centre, La Trobe University.

The aim of this major new research project is to develop and evaluate the effectiveness of an education program that trains people who provide decision-making support so that the quality of their support improves and results in better outcomes for the person who requires decision-making assistance.

While the project will specifically explore this for people with learning disability and acquired brain injury who require decision-making assistance, the findings are expected to have applicability to a broader range of people with cognitive impairment.

Comprehensive 7 steps/Strategy Processes in support for decision-making Bigby and Douglas.



The first phase of the project involves the development of the evidence-based education program and resources that will be delivered and evaluated. The second and third years of the project will involve delivering the education programs and gathering evidence to assess the effectiveness and impact of the education program. Measures include both qualitative changes (scored from administration of internationally accepted instruments) under a rigorous prospective experimental and control group design, and qualitative data on the benefits experienced by the person supported and the supporter.

For further information about this project see link at left.

<http://www.latrobe.edu.au/lids/research/support-for-decision-making/decision-making-support>

5. Supported Decision-making Projects: Case Studies

My travels took me to Sydney, Brisbane, Canberra, Melbourne and Adelaide, to meet staff responsible for six SDM projects, each with a very different focus and offering insights for potential developments in the UK. I was privileged to observe practice in four of these which I have described in more detail.

1 ADACAS (ACT): SDM 'Link and Learn' Project.

I was grateful to Fiona May, CEO, ADACAS (ACT), Kate Rea SDM Project Co-coordinator, and Tina Dowse, Project Officer, for their time and particularly for inviting my involvement in a peer workshop for supporters.

This project is of particular interest because of the following distinctive features:

- ADACAS has undertaken a number of SDM trials over the past four years, and demonstrated the added value of being placed with a well-established independent advocacy service;
- practice which builds the capacity of the person with learning disability to become 'decision ready';

- training and support focusing on the skills and capacity development of natural supporters;
- SDM support for people with psychosocial conditions and chronic mental illness who are socially isolated. The current two-year programme, which is being evaluated, aims to support 50 people in this category.

At the time of writing ADACAS has recently received funding for a two-year SDM pilot for people with early-onset dementia.

Philosophy and practice

The ADACAS approach to SDM is flexible and person-centred, based on 5 key principles, which provide the framework for giving decision support. Decision-maker supporters participating in the SDM programme are expected to sign up to these principles:

- Every person has the right to decide as far as they are able.
- The right to decide can be exercised with support.
- Equality – decision support is about enabling a person with a disability to approach decision-making with the same expectations, freedoms and responsibilities as those who do not have a disability.
- Respect the decision maker and their decision. To support a decision you must be able to respect the values, experiences and goals of the decision maker. You must do this even when you do not share them, or agree with the decisions they make.
- Give only as much support as is needed, so that the decision maker remains active and engaged in their decision. Recognise that different decisions will need different supports and levels of support may change over time.

SDMS: Facilitation, education and support

The focus on learning about the process of decision-making and support for decision-making aims to sustain practice over time and is not directed only towards achieving a specific goal. It builds on the long term, trusting relationship between the person with cognitive disability and their chosen supporter (usually a family member or friend).

This model of support for decision-making places emphasis on small peer group workshops for decision makers and both separately or together with family member supporters. The service offers ongoing mentoring for the supporter.

Training programmes also target a range of professionals including Trustees and Guardians, who may also have a supporter role. In addition the project's outreach programme aims foster social inclusion by build community awareness and education about the rights of people with cognitive disability to be supported and assisted to make their own decisions.

Capacity building - decision readiness

Decision-making is regarded as a skill that we all learn and so is supporting someone to decide.

The SDM model recognizes that many people with a learning disability have grown up with little opportunity to gain experience of decision-making in their lives, often lacking the skills to make even the most simple of decisions. Without this ability, the opportunity to engage in NDIS processes and to be receptive to other opportunities is lacking. Small peer group workshops help participants learn what it is to make a decision and resources have been developed including workbooks and an online Decision-making Tool 'Supporting my decisions'.

Case Study: capacity building for supporters – experiential learning

I was invited to sit-in on the second of three workshops with four family member decision 'supporters'. Participants described how the first session had influenced their attitudes and behavior to 'do things differently' with positive outcomes for the person they supported and for themselves.

'Learning to do things differently'

Mrs. M recounted that the first (SDM) workshop had made her think a lot about how she spoke to her son, now 18 and his rights as an adult. She realized she still talked to him as if he were a child and made a conscious decision to change - with positive results. The trainer asked Mrs. M to share an example. Mrs. M told the story of how every Sunday the family go out for a meal at a restaurant, they all smarten up except for her son who insists on wearing the same dirty old brown sweater he has worn all week. Every week she nags him to change his clothes but he refuses. Over the last two weeks she has had different conversations with him about how he feels about his clothes and how he looks and has said nothing about the Sunday outing. When Sunday came he chose to wear something different and looked in the mirror, proud of himself.

During the session participants were given case studies to discuss, illustrating both good and bad practice. These provoked participants to reflect on what they did in similar circumstances and the trainer was skilled at drawing out and endorsing the learning. The session finished with participants being given some tips for doing things differently that had emerged from their discussion during the session. Reflective practice is integral to the SDM methodology in this service.

Relationship between SDM and Advocacy

Fiona May explained the mutual benefits from embedding the Supported Decision-Making Project alongside the ADACAS independent individual advocacy service. For example, SDM can have limitations in helping the person to fulfill their goals, particularly when the resources of other agencies are involved. Advocacy is able to step in and provide short-term, decision-specific support to ensure the person has full information about their rights and that their voice is heard.



2. Uniting Jaanimili NSW. Approaches to SDM with Aboriginal and/or Torres Strait Islanders.

'Jaanimili' is a Gumbaynggirr word from the mid north coast of NSW meaning 'gathering together'.



The SDM program works closely with members of the Aboriginal community living with a disability, to build their confidence and assist them with decision making when transitioning onto the NDIS. This is sensitive work for this community, who have very specific cultural approaches to individual decision-making.

This project is run by Jaanimili, the Aboriginal Services and Development Unit in Uniting. This project is of particular interest because it brings a 'cultural lense' to the concept of SDM and in so doing takes a community development approach, and is the first project of its kind in the world.

I met project coordinator Kerin Carpenter, at its centre in Campbelltown on the southern edge of Sydney, which has the highest Aboriginal population living with a disability within NSW. The project is in its second phase of development having been evaluated by the Department for Ageing, Disability and Home Care, NSW. There are also two partner projects further down the south coast in NSW. It has such great success it has now been adopted across the state, and is currently being rolled out to two new projects.

A community development approach to SDM

Kerin explained how the project has had to find creative ways to engage with the community and gave the example of setting up a 'kids club' with parents to gain their trust. The club provided a range of opportunities for SDM, including one-to-one work as well as group work. The club became a focal point to build decision-making capacity for parents and children, helping parents to overcome their anxieties about giving their children choice and confidence building for children who learnt to negotiate with each other and make decisions about activities.

The project runs a carers support group which uses experiential learning on 'How do you make decisions?' helping parents understand how important it is to give their child, from being a baby, the opportunity to make simple choices, to build up decision-making skills.

Kerin talked about the need to challenge parents not to 'wrap their child up in cotton wool' but to weigh up risks, to see if they are real and what can be done to reduce them.

The decisions we make whether big or small will assist us to become the people we are and live the types of lives we want to live. When someone else makes decisions for us we feel we have no control and may become frustrated and confused.

When we make our own decisions we feel more in control,
we become stronger and more confident and take more responsibility.
Jaanimili: 'SDM Handbook for supporters'

Kerin plans to produce digital stories, recording the conversations with participants and to make a film.

'We are natural story-tellers and artists and this is what I use with families - stories, not theories or models!'

Kerin went on to describe how systems such as the NDIS can be culturally insensitive to the exclusion of minority ethnic groups. The NDIS relies on access to technology by people with disabilities and their supporters to build their 12-month plans for use in the 1-hour interview with the assessors, which is not always accessible to all communities. Kerin has worked positively with local NDIS staff to develop an alternative planning tool for families to prepare in advance of their interview.



3. Greystanes Disability Services: Person-centred Active Support (PCAS) model.

The Greystanes Disability Service at Leura in the Blue Mountains, provides supported community living and home support services for people with severe and complex learning disabilities. SDM practice is of particular interest within this service because of its:

- Person-centred Active Support (PCAS) methodology and philosophy to facilitate decision-making for adults with severe and complex learning disabilities.
- Its innovative use of assistive technology to enable people with severe communication issues to express their views, feelings, will and preferences.
- The transformation of services from traditional/paternalistic to embracing the right to decision-making support.

At Greystanes I met John Le Breton, CEO, an inspirational proponent of 'Person Centred Active Support' (PCAS) and former NSW Public Guardian. He explained that transforming his service has meant challenging the assumption that individuals with severe cognitive impairment are incapable of engaging, when in fact they have lacked the opportunity to make decisions.

Person-centred Active Support does not see the person as perpetually incapacitated, but capable of participating and making simple choices if given the right amount of support and no more.

John Le Breton

Capacity building

Person-centred Active Support does not see the person as perpetually incapacitated, but capable of participating and making simple choices if given the right amount of support and no more. All individuals with cognitive impairment, no matter how severe, are regarded as having the potential to build up capacity to make even small decisions. PCAS aims to fully engage individuals in activities to enable them to learn to make even the most simple choices for themselves, supporting them to express their will and preferences. PCAS practice was initiated by Julie Beadle-Brown at the Tizzard Centre, in collaboration with others including the late Jim Mansell, Melbourne University.

“It is through experience that the person gains a repertoire of things they recognize and begin to make choices”.



Supporter Responsiveness

The Greystanes Service partners La Trobe University and the Tizzard Centre, Kent University in research, which has provided empirical evidence of the direct relationship between PCAS and decision-making ability. Research, by Jo Watson, Deakin University, highlights the importance of supporters (staff and family) having positive perceptions of the ability of those they support to make decisions, ‘Supporters who held such perceptions, predominantly demonstrated greater responsiveness to expressions of will and preference overall, than those who did not hold these beliefs’.

Training

Staff training focuses on the importance of learning through close observation of the person and exploring how they express their preferences and communicate them non-verbally. This enables staff to offer options and choices even on a very basic level. In small group living accommodation, staff form communication groups to support each other to understand the person, to build up the capacity of individuals to make even small decisions.

Training packages have been developed for supported decision-making with La Trobe University, including an online training resource, ‘Every Moment Has Potential’. This is designed for disability support workers and introduces them to the ‘Four Essentials of Person-centred Active Support’. The resource has five modules including activity videos, exercises and reflective questions. It can be used from smart phones, tablets and computers. A workbook, facilitators guide and additional resources can be downloaded from the site at no cost via the link: Every moment has potential. Person-centred Active Support, Online Learning Resource.

Assistive technology and empowerment

Assistive technology also has a key role in transforming the ability of people with severe communication difficulties to express their feelings, will and preferences.

I met two young women who were having their nails painted (neither with verbal ability). Their supporter explained that they had discussed who would go first by using voice assistive technology. When I asked who had wanted to go first, one very quickly responded by pressing her 'gadget' telling me in no uncertain terms that she had wanted to go first.

4 Practical Supported Decision Making Facilitation Model South Australia.

The final stage of my journey took me to South Australia - the 'trail blazer' in this evolving SDM world. The first model was trialed between 2010-2012 by the South Australian Office of the Public Advocate, supported by the South Australian SDM Committee under the provision of guardianship legislation and further developed by the Office of the Health and Community Services Complaints Commissioner (SA) (HCSCC), 2013-14.

The SA model has two distinguishing features, which make it of particular interest:

- the development of the role of the SDM 'facilitator' in supporting the decision-maker and their supporter;
- the development of a time-limited SDM Agreement as a tool for goal setting and future planning.

The 2015 evaluation noted that, for facilitators, 'mentoring was a crucial element in the development of skills and in developing the confidence to put them to use.'

Findings from the evaluation indicate that:

- The 'Agreement' is a viable tool and that its use proved positive for participants and supporters.
- Training for facilitators is essential, given their complex role in relation to supporting the decision-maker and mentoring the supporter to develop their decision-making support skills.
- In-depth training and mentoring for SDM facilitators to develop their skills and confidence is crucial.

I visited Cher Nicholson, who had played a pivotal role in the design and delivery of the SA pilot having been employed as the first senior practitioner and project coordinator. I was aware that the model had evolved and wanted to find out how it worked. Cher now runs her own consultancy, ASSET (SA). The agency offers specialist training for disability service staff to facilitate support for decision-making for users of their services.

Cher invited me to accompany her to several meetings with decision-makers, their trainee facilitators, and supporters, to gain insight into how the model works in practice.

*Cher Nicholson, ASSET (SA)
Supported Decision Making.*

<https://assetsa.wordpress.com/articles/supported-decision-making/>

The Agreement

A condition of inclusion in this service is the ability of the decision-maker to understand and commit to what is involved. This includes the: wish to receive help with making decisions; ability to express the sorts of decisions the person would like help with making and the ability to choose who they would like to support them. Decision-makers are self-selected through visits and talks to disability service users.

The Agreement has a number of key functions. It sets out expectations of the decision-maker, the facilitator and supporter/s. It provides a tool for identifying the decision-makers hopes, dreams, will and preferences under each of the main headings: lifestyle, health, money, accommodation, study etc. These can be changed at any time. The Agreement is for an initial six months but can be extended or finished earlier. All participants, facilitator, supporters and decision-maker sign the Agreement.

How does the 'Facilitation' model work?

Each decision-maker has a professional facilitator who they usually meet weekly to develop the Agreement, which focuses on the short and longer term goals they want to achieve and their priorities. The facilitator assists the person to decide on who they would like to have as their supporter/s. This is usually a family member and/or friend. The facilitator monitors progress towards achieving the goals set out in the Agreement, and assists discussions between the decision-maker and the supporter. This might include referring decision-makers and supporters to appropriate services (e.g. housing services, community activities). Facilitators act as coaches for supporters, ensuring that they develop the knowledge, skills and attitudes necessary to support the individual in making their own decisions.

The supporter also enters into the Agreement, their role being to assist in gathering information to inform choices, to be involved in communicating the person's decisions to other bodies and vice versa and to help the person in practical ways to fulfill their decision. The model takes a community development approach, aiming to create opportunities for the decision-maker to participate in community activities, develop supportive relationships and reduce reliance on disability services.

"Supporters felt the benefits from having support to develop their own skills as supporters. Access to this type of support may be a necessary component of a successful SDM model'. HCSCC 2015

All facilitators have specialist training provided by Cher and colleagues at ASSET, who also provide a coaching or mentoring role to trainee facilitators. A trainer also has a monitoring role and may attend the first couple of meetings between the facilitator and decision-maker and supporter.

I attended three SDM meetings with individuals at different stages of participation in the SDM programme. Cher explained that meetings are often arranged in community spaces, such as libraries and community centres, so decision-makers can become more open to opportunities.

Case 1: Tom's formal meeting to sign the Agreement

We meet in an Aboriginal community arts centre, Tom's choice, as he wanted to view the exhibition after the meeting. Cher explained that this was a larger than normal meeting as two of Tom's service managers were attending as formal supporters because it was important that they committed to SDM principles and understand what is involved in supporting Tom to achieve his self-determined aims set out in the Agreement.

Wendy, Tom's facilitator, has been meeting with him every week to draw up the SDM Agreement (referred to as the 'Contract') and to select a supporter, as he has no family or friends willing or able to take on the role. The Contract sets out his short and longer-term aims and his priorities. Tom was reminded that he can make changes to his aims and plans at any time and that the contract is for six months but could be extended or ended beforehand if that is what he wants.

Tom's expressed will and preferences

Tom's short-term aim is to build up his physical strength by going to the gym for weight lifting training. He is also wants to learn how to read and write and has an interest in art, swimming and wants to go on holiday but the gym comes first.

Alan (Tom's decision-making supporter) asked Tom what was most important to him at the moment. Tom said that he was not happy with the arrangement to receive his twice-weekly allowance of \$15 cash from the person managing his money. He would like that increased to \$20 twice a week or better still he would prefer to be able to draw up to \$40 a week whenever he wanted. This would give him more flexibility and choice with his activities. Tom agreed that Wendy should invite the person managing his money to come to their next meeting to put the proposal to him. Tom also asked for a mobile phone and Alan agreed to contact the Aboriginal Council, which sometimes funds audio equipment. Wendy agreed to write up a summary of the meeting, noting what tasks everyone has and follow up.

The Agreement was signed by all present and Tom announced happily
"Now I'm The Boss"

Case 2: Mike's regular SDM meeting.

In relation to this case it is useful to know that Cher travels with her guide dog, which become fairly central to the conversation with Mike.

Mike is a wheelchair user with complex health issues and cognitive difficulties. He has a Guardian who is happy with his participation in the SDM programme. Mike's trainee facilitator is John and his supporter is Kirsty (a volunteer). We met at a quiet restaurant in the area close to where Mike lives in a small group home. I'd met Mike with other 'peer consultants' at a workshop after the AGAC conference in Sydney and he remembered our conversation. Cher invites people with lived experience to be Peer Consultants at her training sessions for facilitators and other professionals.



Mike's will and preferences.

Mike signed his Agreement some time ago. His ongoing priorities are to own a dog and to get a job.

He likes Cher's dog a lot and made a great fuss of him. Some time ago Jo had arranged for a 'pet therapy' dog to visit, but Mike was not considered a priority for the service so visits did not continue. The discussion centred on the practicalities of owning a dog. I was regarded as a 'community asset' and invited to share ideas as to a way forward for Mike to achieve his goal. I had observed how Mike responded to Cher's dog and asked if he knew a dog owner nearby who might be glad to let him 'dog walk' on a regular basis. Mike really liked the idea and John said he would be happy to help him to find out and go dog walking with him. He suggested this could help Mike learn about what is involved in looking after a dog, and it might even lead on to him earning money as a dog walker. It was agreed that Mike and John would do some local research before the next meeting.

Case 3: Sean's regular SDM support meeting

Sean is a young man who was described as having suffered a terrible trauma when he was a child. He had been moved around a lot but has been settled in a small group home for the past two years. Sean has only recently signed the 'Contract' after working on it for a few months with Bruce, his facilitator. Sean's chosen supporters are his grandmother and a friend.

In the meeting, Bruce and Sean go through Sean's plan, and see what had been achieved under each heading and whether the goals were the same or had been changed.

Activities / holiday / money

Sean wants to go fishing and to buy a rod. He is unhappy that his Trustee Administrator manages his activity money and wants it to be transferred into an account of his own so he can buy one. He states that he needs the rod quite soon because he is going on holiday to Cairns where a charter boat has been booked. The holiday is funded by NDIS but they won't cover the cost of a rod. Bruce agreed to speak with the Trustee about releasing funds for a rod and would raise the issue of access to his activity fund.

Study / work

Sean wants to learn to read and write as he thinks it will help his employment prospects. He did have some work experience with a butcher who promised to pay him and only did so for the first day. Bruce gave Sean the good news that another butcher has made a genuine offer to take him on for work experience. Sean agreed to make a new work plan at the next meeting.

5. Financial Decision-making Support Project. Office of the Public Guardian, NSW

In Sydney I met Justine O'Neill, Assistant Public Guardian, who is responsible for initiating and overseeing a number of supported decision-making projects in New South Wales. Justine administers the Australian National Supported Decision-making Network forming a community of interest and invaluable list of contacts.

The NSW Public Guardian is working with NSW Trustee on a new Supported Decision Making Project (2016), funded by Family and Community Services (FACS) for 12 months. It has two teams, one dedicated to financial decision-making, the other to providing education. I met the project staff team led by Jonathan Harverson, senior project manager with Kate Flannery, trainer. This project is of specific interest because it aims to:

1. Build the skills of people who need help to make financial decisions.
2. Provide training to service providers to help promote and deliver supported decision-making.

6. OVAL SDM: supporting socially isolated people through the NDIS system, Office of the Public Advocate, Victoria.

In Melbourne I met John Chesterman, manager, Policy and Research, Office of the Public Advocate, Brenda Bergan, SDM Project Co-ordinator and Michelle Browning, researcher, to learn about the OPG's programme for supporting decision-making. The OVAL project is of specific interest because it aims to use volunteers to support socially isolated people with cognitive disabilities who wish to receive support with making their NDIS support plan. The pilot aims to recruit 60 participants.

6. Issues Emerging from Roundtable Discussions

I was invited to participate in the following multidisciplinary roundtable and stakeholder meetings on SDM at which key issues for policy, practice and research were discussed:

- Public Attorney, Queensland, Brisbane
- Mental Health Community Coalition, ACT, Canberra
- Senior RightsVic, Melbourne, Victoria
- La Trobe University – Melbourne, Victoria
- Flinders University Law School – Adelaide, South Australia

Whilst each event focused on a specific topic, the discourse was wide-ranging and nuanced, making it impossible for this report to do justice to the high quality of the papers delivered and the debate that followed. I have simply headlined a few of the key issues emerging from discussion and highlighted some key questions raised. I am aware of the considerable body of recently published work as well as work in progress by researchers, philosophers, ethicists, lawyers and others to advance thinking on these thorny issues at a national and international level.



Prof. Jacinta Douglas at
LaTrobe University
Roundtable 8.11.2016



These issues intimately affect the lives of people with lived experience of cognitive disability and their informal supporters. It is essential therefore to find ways to express these complex issues in easily understood ways and to hear their views on these matters.

Key issues:

Capacity assessment and capacity building.

General concern was expressed that many psychiatrists and lawyers (with responsibility for assessing capacity) lack an understanding of capacity building and the potential for supported decision-making to avert applications for guardianship. Functional capacity assessments should be designed to identify the decision-making support needs of an individual.

The concept of 'autonomy'.

The notion that we act as autonomous individuals was challenged as a Western concept, reflected in law in Australia, Europe, Canada and the US. It fails to recognize the culture of shared or community decision-making in much of the rest of the world and for members of these communities living in multicultural societies such as Australia and the UK. In reality, few of us in the West make independent decisions, raising the issue of whether formal provisions should recognise 'shared' or 'co-decision-making'.

Interpreting 'will and preferences'.

Case based discussions during and subsequent to the AGAC conference, indicated that the separate concepts of 'will' and 'preference' are not well understood, and generally conflated. The question of 'how to avoid making a 'wrong' interpretation for someone lacking verbal communication skills or whose use of language is diminishing' was recognised as an issue to be addressed through professional development and training. Further more, compliance with Convention General Comment No.1 in relation to hard cases (for example where the person may lack consciousness) gave rise to the thorny question of whether it is possible to make a 'best interpretation' of the person's will and preference or and whether in reality this amounts to 'substitute decision-making' rather than 'representation'.

Safeguarding: compliance with Convention Art.12 (4)

A major concern was expressed about the high level of abuse identified in the ALRC report on 'Elder Abuse' and fears that opportunities for abuse could increase with the formal appointment of 'decision-making supporters'. Solutions to finding safeguarding provisions that would be proportionate and appropriate in relation to the appointment of a 'decision-maker supporter' were under active consideration. Of central concern was the question of how to identify psychological abuse, which is invisible and hard to evidence, for example, 'undue pressure' and 'dominance'. The pressures may be subtle, given the imbalance of power in the relationship between the supporter and person with cognitive impairment. A common example given was the pressure exerted by relatives on a person with dementia to enter a care home against their will and preference, often in the face of a crisis for the primary supporter. This distressing situation gives rise to the ethical question of whose rights take precedence. A suggested solution is that we need to move towards a 'relational' analysis of decision-making and offer approaches to conflict resolution through mediation and negotiation.

Sustaining support for decision-making

Discussions centred on the demand for resources to fulfill and sustain the right to SDM for the many thousands of adults with cognitive disabilities, especially for those people who have no natural supporters. SDM rights are regarded as integral to accessing all other CRPD rights and as such implementation of Art 12 is pivotal.

There is no one point at which learning about SDM begins and ends – it is a complex human rights issue with many lessons to be learned from the body of research, evaluations and experiences from Australia and elsewhere across the world'. Terry Carney



*Visitor in the
Wombat State
Forest. Listening.*

7. Conclusions and Recommendations

The human rights of people with cognitive disabilities are systematically undermined because it is commonly thought that they are not capable of expressing their wishes or that they lack the capacity to make decisions. However, the Convention's Art.12 applies to everyone with cognitive disability, no matter how severe. The forthcoming review of UK compliance with the UN monitoring Committee (2017) and recent reviews of capacity/incapacity laws in the UK are driving changes to policy and practice. The UN Committee is expected to give special attention to compliance with Art.12 (3) and (4) as interpreted in General Comment No. 1 on Art 12.

The supported decision-making models in Australia demonstrate positive outcomes for people with cognitive disabilities and their supporters as well as exposing issues to be addressed by more rigorous research than has been accomplished so far. A new series of pilot projects are underway with collaboration between several research institutes and it will be important to follow their progress. However, a whole population response is necessary if negative social attitudes and systemic barriers are to be challenged to recognize people with cognitive disabilities as full citizens with all the same legal rights as everyone else.

We are in a challenging period of change both politically and socially. It will be necessary to make strong alliances and coalitions to take forward the rights agenda for people with cognitive disabilities in the face of competing pressures.

Recommendations

The recommendations in this report attempt to address the issue of 'how' we can build a supported decision-making framework to give full effect to the rights, will and preferences of adults with cognitive disabilities.

It proposes that existing mechanisms and structures in the UK have the potential to adapt to ensure the right to support for decision-making becomes integral to the delivery of services, and identifies opportunities to develop and evaluate demonstration projects, which build on the learning from research and evaluations in Australia.

Recommendations 1-6 below apply to the UK and devolved governments. Each jurisdiction will have its own specific issues which I am unable to address here. However, because of my familiarity with the relevant policy landscape in Scotland I have directed a subset of recommendations to the Scottish Government, which may also be relevant to the development of SDM within disability and equality strategies elsewhere.

The UK, and devolved governments are encouraged to:

1. Convene supported decision-making stakeholder groups to consider how the existing policies, strategies and programmes for people with intellectual and psychosocial impairments might be strengthened; and to clarify what support for decision-making aims to achieve for individuals.
2. Reform capacity/incapacity, mental health and adult protection laws in England/Wales and Scotland to comply with Art 12. by:
 - a) Strengthening SDM statutory principles and codes of practice (with particular reference to AWIA in Scotland);

- and b) having a rebuttal presumption in favour of an individual's will and preferences only to be overridden in exceptional circumstances e.g. emergencies where the individual is at serious risk of causing harm to others (where the state would be negligent under civil or criminal law for failing to intervene) or to themselves; and
- c) ensuring that the legislation makes it clear that no interventions can be considered unless there is evidence that access to the necessary support for the exercise of legal capacity has already been provided,
- d) including a duty to ensure access to training and support for substitute decision-makers, not just information as at present. Such substitute decision-makers must give effect to the rights, will and preferences of the individual (ensuring that what happens is what the person actually wants, subject to the rebuttal presumption mentioned above).
- e) Providing authority for one or more persons to become a decision-maker supporter, with appropriate monitoring and safeguards.
- f) Clarifying limits to the authority of welfare attorneys with regard to deprivation of liberty against the will of the person.
3. Strengthening resources for the provision of independent advocacy.
 4. Priority to be given to piloting community based models for delivering education and support on SDM for non-professional guardians /deputies and attorney (and in anticipation of the formal provision for decision-maker supporters). Appointees have a legal duty to implement the principles in capacity/incapacity laws yet lack support to do so.
 5. UK and devolved governments to fund collaborative research programmes to pilot SDM delivery systems in partnership with the relevant research institutes in Australia. Gaps in research relate to the people with dementia. In the UK consideration should be given to targeting SDM trials for people living with dementia and with learning disabilities as the largest groups subject to the over-use of legal provisions for substitute decision-making.
 6. Develop a National Framework for Supported Decision-making Practice to be included in Codes of Practice for capacity/incapacity laws.

Health and Social Care Partnerships to:

7. Include SDM principles and skills training for all practitioners who have direct contact with people with a cognitive disability and their primary supporters.
8. Public services to Include supported decision-making principles and skills development within equalities training, especially health, social care and legal professionals including the judiciary.

Third Sector agencies and disability rights groups representing people with cognitive disabilities and carers to:

9. Model best practice in support for decision-making; raise awareness of Art.12 issues with their own constituents and create platforms for wider dialogue with public, professionals and politicians.

Statutory and non-statutory bodies to:

10. Ensure that the design of SDM policies and implementation plans have the full participation of people with cognitive disabilities and their informal supporters.

2. The Scottish Government is encouraged to:

Take steps to implement its commitment to supported decision-making in the following National Strategies.

1. National Mental Health Strategy 2017- 2027

- a) Commitment 34: 'Adults with Incapacity legislation should fully reflect the requirements of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), with particular emphasis on provision of supported decision making, addressing issues around deprivation of liberty and the interaction of AWI legislation with the legislation on mental health and adult support and protection.' Scottish Government National Mental Health Strategy 2017-2027 (March 2017)
- b) Address the ongoing serious shortage of Mental Health Officers (MHOs). MHOs provide essential safeguards for the rights of people with cognitive disabilities under incapacity and mental health laws.
- c) Address gaps in the provision of independent advocacy in the community. Demand is increasing while funding has either been reduced or frozen. People with cognitive disabilities are entitled to independent advocacy under the Mental Health (Support and Treatment) Act, it is an essential safeguard.

2. National Dementia Strategy 2013 - 2016

- a) The strategy adopts the principles set out in the Charter of Rights for People with Dementia and their Carers in Scotland, which reflect UNCRPD and European Convention on Human Rights principles. In summary, 'people with dementia and their carers have the right to:
 - participation, including rights to accessible information and support to participate in decisions that affect them;
 - live as independently as possible with access to community facilities
 - full participation in planning care; and
 - be assisted to be involved in policy-making.'
- b) The potential for SDM to become integral to the role of Dementia Link Workers/ Dementia Practice Co-ordinators, should be explored.

3 Keys to Life- Scotland's Learning Disability Strategy 2013-2023

The principles of choice, control and independence for people with a learning disability are at the core of this 10-year strategy. The Implementation Framework 2015-2017' includes Strategic Outcome 2 – that people with learning disability are treated with dignity and respect, and protected from neglect, exploitation and abuse; and Strategic Outcome 4 – that People with Learning Disability are able to participate in all aspects of community and society. The next implementation framework is currently being developed. It is strongly recommended that the opportunity be taken to include provision for supported decision-making. As this report indicates, there is considerable expertise and resource to draw on from SDM models of practice in Australia, which mainly involved people with learning disabilities, their families and care staff.

Appendix 1

Abbreviations and glossary

ACT:	Australian Capital Territory
ALRC:	Australian Law Reform Commission
Art.12:	Article 12 of The United Nations Convention on the Rights of Persons with Disabilities, 'Equal Recognition Before the Law.
AWIA:	The Adults with Incapacity (Scotland) Act 2000
EAP:	The Essex Autonomy Project
MCA:	The Mental Capacity Act 2005 (England and Wales)
MWC:	Mental Welfare Commission, Scotland
NDIS	National Disability Insurance Service (Australia)
SDS	Self Directed Support (UK)
SDM:	Support for Decision-making (Supported Decision-making)
PoA:	Power of Attorney
UK:	The United Kingdom of Great Britain and Northern Ireland
UNCRPD/	The Convention: United Nations Convention on the Rights of Person's with Disabilities.
The UN Committee:	The United Nations Committee on the Rights of Persons with Disabilities

Terminology

Advocacy (non-legal): independent advocacy is about speaking up for an individual or group. It's a way to help people have a stronger voice and to have as much control as possible over their own lives. Independent advocates may also speak on behalf of people who are unable to do so for themselves.

Decision maker: refers to a person with cognitive disability. Not all individuals with cognitive disability will experience difficulties with decision-making.

Decision-maker supporter: refers to the person or persons chosen by the decision-maker to assist with making and acting on self-determined decisions (family member/s, friend, professional).

Decision-making capacity: an individual's decision-making capacity relates to their ability to make decisions about things that affect their life. To have decision-making capacity means that the individual can understand a decision, the available choices, the consequences of any decision they make and can communicate this decision.

Dyad: this refers to the decision-maker and supporter relationship.

Facilitator – refers to a trained professional who facilitates learning about decision-making rights and skills for both the person with cognitive impairment and their chosen supporter.

Formal supporters: paid health or social care staff; legally appointed attorney, guardian or trustee.

Guardians/Deputy: One or more persons may be appointed by a court with specified powers to make a 'best interest' substitute decision/decisions for a person with mental disorder who has been assessed as lacking the capacity.

Informal/natural supporters: family member/s friend, volunteer (non-professions)

Legal capacity: is the ability to hold rights and to make decisions that are respected and capable of being enforced under the law (e.g. signing contracts and agreeing to medical care and treatment).

People with cognitive disability/impairment: includes people living with the experience of the following conditions: learning disability (the term used in Australia is 'intellectual disability'), severe traumatic acquired brain injury (acquired brain injury 'ABI'), progressive neurological conditions/dementia, psychosocial conditions and severe mental ill health.

Persons with disabilities: UNCRPD Art 1.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'. In this report the preferred terms used for 'cognitive impairment' are 'cognitive disability' or 'decision-making difficulties' (used interchangeably).

Public Trustee: appointed under guardianship and administration law in Australia with authority to make substitute financial decisions.

Substitute decision-making: occurs when a person is officially appointed by law to make certain decisions on behalf of another person. In the UK is someone appointed as a guardian/deputy or attorney under capacity/incapacity laws.

Support for decision-making capacity /supported decision-making: is the process of facilitating a person with decision-making difficulties to develop their ability to make their own decision as far as possible.

Appendix 2: References

Policy

UN Committee on the Rights of Persons with Disabilities, General Comment No 1 (2014) Article 12: Equal Recognition before the Law CRPD/C/GC/1, adopted 11 April 2014.

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

Adrian Ward, Alex Ruck Keene, Alison Hempsey, Colin Caughey, Jill Stavert, Rebecca McGregor, Sabine Michalowski, Wayne Martin , Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK, © The Essex Autonomy Project 2016

<https://autonomy.essex.ac.uk/resources/leap-three-jurisdictions-report/>

UK Independent Mechanism, 'Disability Rights in the UK. UK Independent Mechanism. Submission to inform the CRPD. List of Issues in the UK' (February 2017)

<https://www.equalityhumanrights.com/en/our-human-rights-work/monitoring-and-promoting-un-treaties/un-convention-rights-persons-disabilities>

Mental Welfare Commission for Scotland & Centre for Mental Health Capacity & Law 'Scotland's Mental Health and Capacity Law: the Case for Reform' (May 2017)

Law Commission Report ' Mental Capacity & Deprivation of Liberty' (March 2017).

Harper, C., Davidson, G., & McClelland, R. (2016). No Longer 'anomalous, confusing and unjust': The Mental Capacity Act (Northern Ireland) 2016.

International Journal of Mental Health and Capacity Law , (22), 57-70.

A Fairer Scotland for Disabled People – Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities. December 2016.

<http://www.gov.scot/Publications/2016/12/3778/13>

AGAC 2016 National Conference; Reflections on Will and Preference in Decision-making. Sydney 17/18 October. Link to papers/presentations published.

<http://www.agac.org.au/conference-papers/94-2016-conference-papers> .

Artein-Kerslake A., Flynn E., 'The right to legal agency: Domination, disability and the protections of the Convention on the rights of Persons with disabilities'. International Journal of Law in Context/2017-vol 13/issue 1. 1 March 2017.

Australian Government - National Disability Insurance Service

<https://www.ndis.gov.au/>

Supported Decision Making by WA's Individualised Services.

<http://waindividualisedservices.org.au/>

The Scottish Government Mental Health Strategy 2017-2027

<http://www.gov.scot/Publications/2017/03/1750>

The Scottish Government: National Dementia Strategy 2017-2017

<http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>

Scottish Government. The Keys to Life – Improving quality of Life for People with Learning Disabilities. 2013 – 2023. June 2013

<http://www.gov.scot/Publications/2013/06/1123>

PLEASE NOTE RE: LINKS.
Website Links were correct at the time of publication. However, web pages may have been superseded, moved, or changed, invalidating these links. Please navigate to the 'home page' of the site and search from there.

SDM Practice

C. Bigby, & J. Douglas, (2015). Support for Decision Making – A Practice Framework.

La Trobe University

Julie Beadle-Brown (2015) Supported Decision-making in the United Kingdom: Lessons for Future Success, *Research and Practice in Intellectual and Developmental Disabilities*, 2:1, 17-28, DOI:

10.1080/23297018.2015.1040995 To link to this article:

<http://dx.doi.org/10.1080/23297018.2015.1040995>

Mansell Jim & Beadle-Brown Julie Person-centred Active Support: Enabling and Empowering People with Intellectual Disabilities. Jessica Kingsley Publishers, London, 2012, pp. 224. ISBN 9781849051118.

Watson, J. (2016). Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws*, 5(6).

Resources

Advocacy for Inclusion: Decision-making App. A resource to support independent advocates and 'self-advocacy'. The App takes the user through a decision-making process to make their own decision. It can be used independently or with a supporter.

www.advocacyforinclusion.org

Scope with Carers Australia VIC: 'The Creation of Sean's Decision' – 3 written booklets to assist legal professionals, service providers, and carers. Plus six one-page concise, plain English information sheets for disability support workers, three multimedia companion videos for each booklet resource.

<http://www.scopeaust.org.au/research-project/decision-making-support-building-capacity-within-victoria/>

ADACAS Support my decision;

www.support-my-decision.org.au

On-line resource provides a tool to look at simple modules on Learning to decide; getting support, making a decision, support a decision.

SCOPE 'Listening to those rarely heard'.

<https://vimeo.com/21176882>

Inclusion Melbourne: 'It's my choice' Toolkit for people with intellectual disabilities'. Series of booklets and YouTube Aims to help those applying to the National Disability Insurance Service.

<http://inclusion.melbourne/resources/choice/>

Mental Welfare Commission for Scotland. Good Practice Guide: Supported Decision-making. (2016)

<http://www.mwscot.org.uk/publications/good-practice-guides/>

Self-Directed Support Guidance

www.sdsscotland.org.uk

In Control – Self Directed Support (England/Wales)

<http://www.in-control.org.uk/support/support-for-individuals,-family-members-carers/what-is-self-directed-support.aspx>

Mental Capacity Act (MCA) Directory. Making Decisions – supported decision Making: Social Care Institute for Excellence.

J. Killeen 'Dementia; making decisions. A practical guide for family members and friends with powers of attorney, guardianship or deputyship'. Alzheimer Scotland, 2012.

http://www.alzscot.org/information_and_resources/information_sheet/2413_dementia_making_decisions_-_a_practical_guide

WHO QualityRights 'Realising supported decision-making and advance planning. Training to act, unit and empower for mental health (Pilot version)

<http://apps.who.int/iris/bitstream/10665/254808/1/WHO-MSD-MHP-17.8-eng.pdf?ua=1>

Research

T. Carney. 'Clarifying, Operationalising, and Evaluating Supported Decision Making Models, Research and Practice in Intellectual and Developmental Disabilities' DOI 2014 : 10.1080/23297018.2014.902727. To link to this article:

<http://dx.doi.org/10.1080/23297018.2014.902727>

C. Bigby, J. Douglas, T. Carney, S. Then, I. Wiesel, E. Smith (in review) Delivering decision making support to people with cognitive disability – what has been learned from pilot programmes in Australia from 2010 – 2015.

South Australia Office of the Public Guardian. Resources.

Supported Decision- making.

http://www.opa.sa.gov.au/resources/supported_decision_making

J. Killeen. Dementia; autonomy and decision-making. Putting principles into practice.

Research summary and recommendations for policy and practice. Alzheimer Scotland. 2012

http://www.alzscot.org/information_and_resources/information_sheet/2413_dementia_making_decisions_-_a_practical_guide

Legal/Capacity Assessment

O'Neill N., Peisah C. (2017) Capacity and the law. 2nd Edition Australasian Legal Information Institute (AustLII) Communities

<http://austlii.community/wiki/Books/CapacityAndTheLaw/>

Australian Law Reform Commission Report: Equality, Capacity and Disability in Commonwealth Laws. November 2014. <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

Australian Law Commission Report: Elder Abuse Inquiry.

<https://www.alrc.gov.au/inquiries/elder-abuse>

M. Browning, C Bigby, J Douglas. Supported Decision Making: understanding how its conceptual link to legal capacity is influencing the development of practice. (based on SDM pilot in Victoria) Journal Research and Practice in Intellectual and Developmental Disabilities. Vol 1, 2014, Issue 1

Alzheimer Europe: 2016 Dementia Year Book. Decision-making and legal capacity in dementia.

LIV Capacity Guidelines and Toolkit: Taking instructions when a client's capacity is in doubt.

Law Institute, Victoria. (Concise) October 2016

<https://www.liv.asn.au/CapacityGuidelines>

Toolkit for assessing mental capacity

A Douglass, G Young, J McMillan. The Law foundation New Zealand

http://www.aspenltd.co.nz/mc/7_C.html

Communication and Assessing Capacity. A guide for social work and health care staff. Adults with Incapacity (Scotland) Act 2000. Scottish Government.

<http://www.gov.scot/Publications/2008/02/01151101/0>

Additional Information

The USA recently established National Resource Centre for Supported Decision-making.

<http://supporteddecisionmaking.org/about>

Appendix 3: Visit Programme

14 October – 7 December 2016

(Churchill Travel Fellowship was for 6 weeks, spread over an 8 week period)

October

Sydney NSW

- 14th-16th Emeritus Professor Terry Carney, Law School, Sidney University and Carole Carney. Orientation weekend
<http://sydney.edu.au/law/about/people/profiles/terry.carney.php>
- 17th-18th Australian Guardianship and Administration Council National Conference; Reflecting Will & Preference in decision-making. Invited by Justine O'Neill, Office of the Public Guardian, NSW. Presented paper on Dementia; interpreting expressed will and preference
- 19th Workshop: Cher Nicholson (ASSET SA)
 Meeting with Craig Sinclair, Researcher, Advance Directives, Rural Clinical School W. Australia
<https://assetsa.wordpress.com/>
- 21st Professor Carmelle Peisah, Capacity Australia,
www.capacityaustralia.org.au/
- 24th Australian Law Reform Commission President, Prof. Rosalind Croucher,
www.alrc.gov.au/
- 25th Justine O'Neill, Office of the Public Guardian NSW; Assistant Public Guardian, Advocacy and Policy, Jonathan Harverson Senior SDM Project Manager, Kate Flannery, trainer and Caroline Smith. Rights Project, Partners Meeting
https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making/sdm-projects
- 26th Project visit; Greystanes Disability Service (Blue Mountains)
 John Le Breton, C.E.O.
www.greystanes.org.au/
- 27th Project visit: Uniting Jaanimili Aboriginal support for decision-making project. Kerin Carpenter, Project Coordinator.
<https://uniting.org/our-services/aboriginal-and-torres-strait-islanders-services/jaanimili>
- 28th Project visit; Kanangra
 Analise Iserief, Project Coordinator, St Vincent de Paul. NSW
 Yvette Proud – Ability Links SDM Trainer (since moved to NSW Council of Social Services. Decision Support Project Officer, Skilled to Thrive.
https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making/sdm-projects/advancing
www.ncoss.org.au

November

Brisbane Queensland

- 31st Mary Burgess, Public Advocate
Kath Dornbush, Principal Research Officer- Decision-making support for Queenslanders with Impaired Capacity.
Stakeholder meeting with Public Guardian, Disability Rights Advocates, etc.
<http://www.justice.qld.gov.au/public-advocate/activities/current/decision-making>

- 1st Dr. Shih-Ning Then, Australian Centre for Health Law Research, Queensland University of Technology

Canberra A.C.T.

- 7th Human Rights Branch, Australian Government. Andrew Simmons and team. Alzheimer's Australia, Jessica Campbell & Priyank Rai, Policy and Research
<https://www.ag.gov.au/RightsAndProtections/HumanRights/Pages/default.aspx>
<https://act.fightdementia.org.au/>
- 8th Project visit, ADACAS Advocacy and Link and Learn SDM Project. Fiona May, CEO; SDM Kate Rea, Project Officer, Tina Dowse, Project Officer.
<http://www.adacas.org.au/supported-decision-making/supported-decision-making/>
- 9th ADACAS SDM workshop for family members. Alzheimer Australia – Government House Reception to launch a dementia report.
- 10th Jodie Griffiths-Cook Human Rights Commission. Stakeholder meeting with Mental Health Community Coalition - Leith Felton-Taylor & invitees
<http://hrc.act.gov.au/childreyoungpeople/#navarticlecontent-1867>
- 11th British Consulate – Cate Setterfield, Science and Innovation Officer

Melbourne Victoria

- 14th John Chesterman, Office of the Public Guardian & SDM project coordinator Brenda Burgen, Michelle Browning, Phd. Candidate, La Trobe University.
www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making
- 15th Prof Christine Bigby, Director, Living with Disability Research Centre, School of allied Health, La Trobe University, Melbourne. Facilitated visit and invited participation and to present paper:
Roundtable 18th November.
<http://latrobe.edu.au/living-with-disability>
- 15th Prof. Magnus Tideman, Halmstad Uni, Sweden.
<http://www.hh.se/english/research/professors/magnustideman.8713.html>
- 18th Roundtable on Supported Decision Making. La Trobe University. Gave presentation on issue for dementia. Dr. Piers Gooding, Social Equalities Institute, Law School, Melbourne University
<http://law.unimelb.edu.au/about/staff/piers-gooding>

21st Dr. Lizzie Smith, Research Fellow
Living with Disability Research Centre, La Trobe University, Melbourne
<http://www.latrobe.edu.au/she/staff/profile?uname=e5smith>

21st Senior Rights Victoria, Jenny Blakey, Roundtable on old age abuse
www.seniorsrights.org.au

Adelaide

26th Sue Jarrad, Independent consultant, Researcher & Churchill Fellow:
hosted weekend, facilitated contacts. Met Kate Swaffer, Chair,
Dementia Alliance International on ADI working group on UNCRPD
<http://www.flinders.edu.au/people/sue.jarrad>

27th Attended Regional Churchill Fellow gathering and lunch.

28th Project visit: Practical Supported Decision-making Facilitation Model.
Cher Nicholson, ASSET SA
<https://assetsa.wordpress.com/articles/supported-decision-making/>

29th Flinders University Law School; Roundtable on: 'Intersections between
elder abuse, guardianship and Advance Care Directives in SA'.
Dr. Susannah Sage Jacobson; Professor Meredith Blake,
UWA Law School,

December

1st Project visit – Cher Nicholson, ASSET (SA) and Debbie Knowles, Trainer

Melbourne Victoria

2nd Returned to Melbourne

6th UNCRPD 10TH Anniversary public lecture, Melbourne 'Disability Rights'

7th Return to UK



*Tree. Melbourne
Botanical Gardens*

Some of the people who contributed.

A Jodie Griffiths-Cook, Human Rights Commissioner

B Andrew Simmons and team, Human Rights Unit, Commonwealth Government

C Financial Decision-making model:

Jonathan Harverson Justine O'Neill, Kate Flannery

D Australian law reform Commission President, Rosalind Croucher

E Mary Burgess Public Advocate, Queensland

F Shih-Ning Then

G Kath Dornbush, Researcher, Queensland

H Piers Gooding

I Sue Jarrad

J Terry Carney & Carole Carney

K Jaanimili, Karin Carpenter

L Ability Links: Brenda Gledhill, Annalise Iserief, Yvette Proud

M Julian & Mary Whittaker

N OPAL Project: John Chesterman, Michelle Browning, Brenda Burgen

O Carmelle Peisah, President, Capacity Australia

P Cher Nicholson & Debbie Knowles

Q Greystanes Disability Service. John Le Breton

R Alzheimer's Aust. Piyank Rai & Jessica Campbell

S Jacinta Douglas & Christine Bigby

T Brisbane Stakeholder Group meeting

U Jan Killeen

V ADACAS Fiona May & Kate Rea

W Mike

X La Trobe University Roundtable



*General Assembly of the United Nations : 10th Anniversary of the
Convention on the rights of persons with disabilities.
2 December 2016*

'The CRPD is the first human rights treaty ratified in the 21st century, with the highest number of signatories in history to a UN Convention on its opening day. Most notably, it is also the first internationally legally binding instrument to specifically address the situation of persons with disabilities at a global level in an effort to promote, respect and fulfil their rights. Since its adoption at the General Assembly in December 2006, the Convention, through its articles, has raised awareness about disability as both a human and a development issue. It marks a paradigm shift, where persons with disabilities are no longer viewed as objects of charity but as active members of society, in charge of their own lives, with free and informed consent. The CRPD is the chief instrument that consolidates the efforts made by the United Nations to promote the equal rights and inclusion of persons with disabilities in all spheres of society'.

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPD10.aspx>

