Supported Decision-Making in social care services for autistic people

J Hennessy, May 2023

This document is about how supported decision-making may be practised in social care settings so that autistic supported individuals can take more control of their own lives and increase their control over the services they depend on.

In writing this document I have adopted the rhetorical device of asking questions (in bold and italics) from the point of view of an imaginary sceptical social care worker/manager in order to focus the discussion.

The legal context, where addressed, happens to be Scottish, however the substantive points about supported decision-making are mostly either jurisdiction-neutral or adaptable to other jurisdictions.

What is supported decision-making?

Simply put, it is helping someone to make a decision for themselves, instead of making it for them. Making a decision for someone else is called substituted decision-making.

Another way to put the idea is that with supported decision-making, decisions are ***made by*** the supported individual. With substituted decision-making, decisions are ***made for*** the supported individual.

Why are we talking about it?

Because it is central to the autonomy of people who receive social care services. Good practice of SDM is a step towards enabling supported individuals to more fully participate in the governance of their care services at all levels.

Since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006 there has been much interest in and discussion about how to ensure that people with disabilities enjoy their rights on an equal basis with others. There has been particular interest in Article 12 of the CRPD which concerns this directly. Article 12 calls for equal recognition before the law, which includes that persons with disabilities enjoy legal capacity on an equal basis with others. Therefore, supported decision-making is a move toward CRPD compliance. The CRPD, while influential, is not yet incorporated into Scots law. There is currently a review of Scottish law related to capacity/incapacity which seeks greater compliance with the CRPD. In terms of current legislation in force now, the most obviously relevant legislation for the practice of SDM includes the Human Rights Act 1998, The Adults with Incapacity (Scotland) Act 2000, Mental Health (Care and Treatment) (Scotland) Act 2003, Adult Support and Protection (Scotland) Act 2007 and perhaps the Equality Act 2010. We will not tackle these in detail in this document. The current review of mental health law in Scotland will very likely significantly alter the legal landscape with regard to supporting the autonomy of supported individuals, whatever their disabilities. The practice of supported decision making will be possible to a greater or lesser extent under a wide variety of legal frameworks, and the general direction of reform is towards CRPD compliance, so the ideas covered in this document will likely be relevant in any eventuality. The Republic of Ireland has already enacted the Assisted Decision (Capacity) Act 2015 in an effort to fulfil its obligation to comply with the CRPD. While there has been much interest and discussion about this new legislation, it has only just been commenced as of May 2023, eight years later, and we do not yet have a body of evidence of how it is working in practice. However, there was a very informative project in South Australia which was completed in 2012 in which they trialled SDM as an alternative to their guardianship system, with very positive results. A brief summary of the project is included in APPENDIX 1.

Why is Supported Decision-Making important?

SDM is important because everyone wants to live the life they choose, not have a life completely chosen for them by someone else. Being in control of one’s own life is called **autonomy**. Nobody has total autonomy and control of their life, but most people can choose where they live and who with, what kind of career to pursue, who to have as friends (or who not to have as friends), how fit they want to be, what they want to eat, where to go shopping, what clothes to wear, whether to eat meat, who to vote for, what newspaper to read, and so on, most of the time. Most people exist within a network of social relationships that make discussing decisions, finding information, weighing up the pros and cons of what to do easy and natural. Perhaps many people never even notice that they have this crucial network of informal support in which they can lead their autonomous lives.

There is a long history of the concept of autonomy under various names. Consider St Thomas Aquinas, a 13th century theologian:

> "The highest manifestation of life consists in this: that a being governs its own actions. A thing which is always subject to the direction of another is somewhat of a dead thing."[1]

And this from Madeleine L’Engle:

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[1] Thomas Aquinas, *On The Perfection of the Spiritual Life*, Chapter 14

> “Take away a man's freedom of choice, even his freedom to make the wrong choice, is to manipulate him as though he were a puppet and not a person.”[2]

More drily, from the Stanford Encyclopaedia of Philosophy:

> Put most simply, to be autonomous is to govern oneself, to be directed by considerations, desires, conditions, and characteristics that are not simply imposed externally upon one, but are part of what can somehow be considered one’s authentic self. Autonomy in this sense seems an irrefutable value, especially since its opposite — being guided by forces external to the self and which one cannot authentically embrace — seems to mark the height of oppression.[3]

The idea of an authentic self opposed to guiding forces from outside captures an important aspect of the autistic predicament. Autistic people are different from neurotypical people in respect of their whole being. This has been recognised among the autistic community since there has been such a community. In the words of autistic self-advocate Jim Sinclair in his seminal “Don’t Mourn for Us”:

> “Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.”[4]

The idea that the mismatch between autistic perspectives and perspectives of the wider society they are embedded in is to a very large degree the cause of disability is the essence of the social model of disability.[5] For those autistic people who depend on them, care and support services, to varying degrees, determine the environment an autistic person is embedded in, and constitute ‘external forces’ that guide a supported individual’s life. That also means that they can, unintentionally, be a cause of oppression and disability, even in the sincere good-willed act of providing support.

Upholding a person’s autonomy involves more than just asking them what they want from time to time. It involves creating an environment in which their lives are shaped by their will and preferences in all respects as a matter of course.

Which decisions does SDM apply to? All of them?

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[2] Madeleine L’Engle, *The Young Unicorns*, 1968

[3] Christman, John, "Autonomy in Moral and Political Philosophy", The Stanford Encyclopedia of Philosophy (Fall 2020 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/>.

[4] https://www.autreat.com/dont_mourn.html

[5] For more on the models of disability, see: Wasserman, David, Adrienne Asch, Jeffrey Blustein, and Daniel Putnam, "Disability: Definitions, Models, Experience", *The Stanford Encyclopedia of Philosophy* (Summer 2016 Edition), Edward N. Zalta (ed.), URL = <https://plato.stanford.edu/archives/sum2016/entries/disability/>.

All the decisions that actually belong to the supported individual. Decisions about daily activities of a supported adult would, by default, be theirs to make, just as they would for any non-disabled adult. Some decisions would not be theirs to make at all, for example, a decision about overall funding of a support package would be for the local authority to make in accordance with law and policy - the supported individual would not (ultimately) get to decide that, even though their views and preferences might well be considered and relevant. However, a decision to challenge that LA decision might very well be made by a supported individual.

Organisational-level decisions, such as a charity’s decisions about what topics to campaign about and what positions to take on them, are more complex to look at in terms of supported decision-making. But the principles of SDM can inform the approach taken to organisational decisions, particularly when the organisation is advocating on behalf of a particular group of people (autistic people in this case), as in the slogan ‘nothing about us without us’.

Some **complex decisions** need analysis. For example: a supported individual decides they want to install a pole-dancing pole in their accommodation, and have pole dancers visit. But whose decision is that? This decision involves many smaller decisions, some of which might belong to the local authority, some of which to the housing association, some of which to the potential pole dancers, some of which to parliament in the form of statutory regulation of such activities, and some to the supported individual. In this case, supporting decision-making is not simply carrying out the will and preferences of a supported individual regardless of any other consideration, it would be informing the supported individual of the necessary steps to achieve their aim, discussing ethics and rights, and which decisions are theirs to make and which are not, and, if it gets that far, even supporting the supported individual to make enquiries and engage with the necessary authorities. Staff and managers should have a good understanding of which decisions belong to whom, so they are well prepared to support individuals to make decisions that are their own to make, and to help supported individuals understand which decisions are theirs to make, and which are not.

So how do we do Supported Decision-Making?

It very much depends on the supported individual, and the circumstances. In general, it is working to maximise the overall choice and control someone has over their lives, so if a service provider is doing that, they are probably doing SDM in some form. There are several ‘ways in’ to working out how to practise SDM. We have already talked about the importance of figuring out which decisions belong to whom. In terms of a rather mechanical approach to support for particular individual decisions, we might make use of the indicators of ‘incapacity’ as listed in the Adults with Incapacity (Scotland) Act 2000 s 6:

> “incapable” means incapable of—
> (a)acting; or
> (b)making decisions; or
> (c)communicating decisions; or

(d)understanding decisions; or
(e)retaining the memory of decisions,

From this definition it stands to reason that if you can help someone sufficiently understand, communicate, remember, make and execute decisions, then one could argue that they therefore *have capacity*, and should be free to make that decision without outside intervention. So SDM can sometimes simply be enhancing these abilities to maximise a person's ability to make a decision.

Of great importance in this list is 'understanding decisions'. Often individuals need more information. Supplying information relevant to a decision is often a crucial part of supported decision-making, e.g.:

> "If you want to catch the bus, we'll need to start walking now."
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> "You're not sure who to vote for? Let's have a look at the party manifestos and talk about what each party says they intend to do."
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> "We could go and visit the other supported individual, yes. Remember that the other supported individual finds noise very distressing, which means we might have to come away, or go into another room, if we want to make a lot of noise."
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> "Are you unhappy with how your support workers support you? They follow a thing called a support plan, and it is written down. Shall we look at it together and see what is in it? We can change it to something better if you don't like it."
>
> "Yes, I'll put pizza on the shopping list. I should just check that you know, if you have lots of pizzas, you can put on weight, which increases the chances of being ill in the future. Shall I remind you of that from time to time so you can control how much you eat? We can work out a plan if you like."

Working out the consequences and implications of a decision is also a huge part of understanding a decision. Very often autistic people have difficulty working out some of the implications of a decision in a world they may find extremely confusing.

'Communicating decisions', and indeed communicating will, preferences[6], wishes and feelings[7] is clearly also of huge importance in supporting people to make decisions. Only when we know what an individual wants is it possible to take steps to help them realise their aims, and that means getting that information from the individual. This is sometimes easy, one can just ask them. Sometimes this can be a much more subtle process of interpretation.

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[6] 'Will and preferences' is the language used in CRPD Article 12

[7] 'Wishes and feelings' is the language used in the Adults With Incapacity (Scotland) Act 2000, s 1 (4) (a)

Often a relationship with a staff member, family member or friend plays a hugely important role in allowing someone's will and preferences to manifest and be given effect to.

But supported decision-making is not just about plugging the gaps in an individual's knowledge and skills for a particular decision. It is about embedding a person in an environment in which they naturally understand what is happening, have easy and ready access to people who listen to and understand them, with people who can translate the outside world into terms an individual can understand, feel safe, comfortable, feel they culturally belong, not too stressed all the time, and are able to easily communicate and exert control over their lives.

Relational autonomy: The importance of close trusting relationships.

> *The bird a nest, the spider a web, man friendship.*[8]

Joe Long on the importance of friendship between support staff and supported individuals in a service provider (emphasis added):

> "Both the staff focus groups and talking groups with supported people found that questions around friendship and affective attachment did not just pertain to relations between supported people but often centred on relations between practitioners and those they supported. These insights led us to consider social care as a form of **relational support** in which interactions and relations with practitioners are central to the lived experience of supported autistic people."[9]

In the South Australian SDM Project, decision-supporters said:

> 'I am a trusted friend, not a carer.'
>
> 'We feel OK about going on [as supporters]. We have a friendship that will last. We love
> him.'

The cultivation of such trusting relationships in which a strong attachment develops between individuals is critical to being able to give effect to a person's will and preferences, and to support their autonomy. In current literature, this is called relational autonomy and is considered best practice among academics and expert professionals. The concept of relational autonomy is a development of an earlier more individualistic conception of

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[8] William Blake, *The Marriage of Heaven and Hell*

[9] Joseph J Long, 'Reflective Practitioners and Participant Observers in Autism Services: Managing Knowledge in UK Social Care'

autonomy, in which a person is to be left alone, undisturbed, to come to a decision that is most authentically their own. In the words of Kong and Keene:

> "An individualistic assumption of autonomy suggests that self-determination demands that we disengage and remove ourselves from social influences that make us who we are - I need to abstract from the influences that make me who I am, like my cultural or family history, my social background, my relationships, so I act from this authentic, oddly isolated core. By contrast, relational autonomy believes this is an impossible task."[10]

While close, trusting, positive relationships are clearly essential to the realisation of autonomy, very frequently autistic people are disabled by our relationships, and we must be careful not to misunderstand what relational autonomy should look like in the context of supporting autistic people. Sometimes, the more individualistic message of 'leave me alone to figure this out for myself' is the correct one in some circumstances. Autonomy-in-relationship should not be interpreted according to neurotypical norms, in which there can be a lot of chit chat, a lot of spending time in close proximity, quick-fire suggestions, too little quiet processing time, and so on, precisely things that can have a disabling effect on autistic people. Some more detailed work about what relational autonomy might look like for autistic people may be useful, indeed much of this work has already been addressed in the National Autistic Taskforce's Independent guide to quality care for autistic people.[11]

The practice of SDM in the South Australian SDM Project resulted in the development of close relationships involving elements of reciprocity, suggesting a greater equality between the supported and the supporter. In the words of one decision-supporter about the person they supported:

> 'They communicate with me, are concerned for me.'

For relational autonomy to be realised, not just any kind of relationship will work, and it is critical to find the right people to provide these relationships. On that subject we need to consider:

Training vs recruitment

Clearly both are important. However, when ensuring a workforce has the right skills and knowledge, traditionally the focus has been on training rather than recruitment practices. Training, when delivered over a day or a week, is likely of very limited efficacy in terms of equipping people, from a standing start, with the skills and knowledge needed to enter into

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[10] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* p 46

[11] https://nationalautistictaskforce.org.uk/an-independent-guide-to-quality-care-for-autistic-people/

supportive relationships with autistic individuals. Consider what Joe Long has to say about the origin of skills in the workforce:

> "...much of the knowledge and skill of practitioners supporting autistic people are acquired through informal learning, peer-to-peer interactions, and ongoing relationships with the autistic people that they support. Many learnt skills such as personalised communication or stress reduction are constituted in the day-to-day support of individuals and may be tacitly held by practitioners rather than consciously deployed."[12]

For what it's worth, training might be developed based on, for example, Kong and Keene's material on 'hermeneutic competencies' of attunement to impairment, recognition of the person as an agent, humility and a willingness to engage in 'open dialogue'.[13] Also narratives of 'respect', 'trust' and 'esteem'.[14] Maybe work on training could be a separate project. All that said, recruiting people with these important qualities in the first place is a huge shortcut which should be taken advantage of wherever possible. Further consideration should be given to the values used in values-based recruitment. Some qualities might be:

- **neurodivergence.** This applies, but is not limited to, autism, ADHD, learning disability, dyslexia, and many more. Neurodivergent supported individuals may well benefit from support from neurodivergent people in order to maximise natural understanding and rapport between supported individuals and staff. Support staff who naturally recognise the needs of supported individuals as real and comprehensible are better placed to meet those needs. Recruitment which explicitly encourages neurodivergent people to apply for a role supporting one or more neurodivergent adults is likely to be a proportionate way of ensuring a staff team which includes neurodivergent members and is unlikely to be discriminatory, provided at least some roles are open to non-disabled applicants.

Lawyer Mary Condell noted the importance of having support from someone with a natural affinity for the supported individual:

> In my opinion, it takes a professional with a deep down belief in the fundamental human right of all persons to make decisions for themselves to accept that, where this particular relevant person is concerned, I am on my own not enough to honour that right of theirs with regard to this particular decision and they deserve the help of another. That other person may be another professional, or, as I found when unable

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[12] Joseph J Long, 'Reflective Practitioners and Participant Observers in Autism Services: Managing Knowledge in UK Social Care'

[13] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* p 58-78

[14] Camilla Kong and Alex Ruck-Keene, *Overcoming the Challenges in the Mental Capacity Act 2005* ch 4

> to understand a question being asked of me by a gentleman with Down Syndrome, the assistance of someone more able to understand him, which in this case was his friend who also had Down Syndrome.[15]

- **experience of having choice and control removed from them, in any context.** Staff who know what it is like to lose control of their lives will be better placed to instinctively understand the importance of autonomy, and recognise when loss of control is happening to others.

- **strong analytical and reflective skills**. Conceptual distinctions such as between stress and anxiety will be better grasped. Understanding of law and best practice is important for confident practice without fear of getting into trouble. We know that many educated, reflective and analytical neurodivergent people are underemployed. Not all will be right for working in social care, and some will not want to, but many will. It is a relatively untapped resource.

- **experience of minority spaces and cultures, especially neurodivergent ones**. Staff and managers who have strong experiential knowledge of what it consists in for a supported individual to be in a non-adverse environment, both physically and culturally. In that way they will be well equipped to recognise when policies, placements or staff are not a good fit for a supported individual. Feeling like one is in a foreign country, poorly understood and isolated, reduces autonomy.

> *The apple tree never asks the beech how he shall grow…*[16]

But staff have to maintain a professional distance don't they? They are paid to do a job, they are not supported individuals' friends. They should not cross these boundaries.

Sometimes close relationships are discouraged in care services. It is thought that being professional is incompatible with being a friend and that supported individuals are best served by maintaining a very firm line between the professional and the personal. However, a recent case in the Court of Protection in England illustrates the danger of the general principle of the importance of boundaries being treated as an arbitrary and inflexible 'rule'. The case concerned a supported individual (P) with Lennox-Gastaut Syndrome, a severe form of epilepsy. He had no family and was supported in a residential home by a staff member TQ. He and TQ became very close. However, a decision was made to move P to a

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[15] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision-Making (Capacity) Act 2015", from *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 222

[16] William Blake, *The Marriage of Heaven and Hell*

different placement, and TQ was prevented from visiting. TQ applied to be P’s Personal Welfare Deputy (a role in England with some similarities to Scottish Guardianship). This application was reacted to very negatively by the care providers and public bodies involved, holding inflexibly to a ‘rule’ that this would always be inappropriate. The Court of Protection found firmly in favour of TQ, highlighting the importance of avoiding misconceptions about what appropriate ‘professionalism’ is, and low-level policy-following leading to unlawful decisions which do not respect the autonomy of supported individuals.

> 17. **The first statement of Ms Williams … almost arrogantly stated, “Staff at ER (including TQ) were involved solely in a professional relationship with P. It is our expectation that professional relationships are time bound, have a distinct role and purpose and have some structure”**. She presented as rigid in her thought process, guided entirely by her belief that it was inappropriate to blur the boundaries of professional carer and friend in any circumstances, referring to TQ as “holding all the power and P as not any”, despite agreeing TQ had never misused that power. She referred to her as being very close to P which ”is endearing but hope all his relationships will be”. Even when prompted under cross- examination **she did not think it was appropriate for TQ to be part of any best interests decision process**. She was quick to draw negative conclusions about TQ without being open minded to other possibilities.
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> 18. **Sadly, I found her to be driven by a policy decision that TQ should play no part in P’s adult life as she had cared for him professionally in the past, to the exclusion of all else.**
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> 20. I have already expressed deep concern about the written evidence of Ms Fairgrieve. Her oral evidence showed the same reliance on a policy decision as Ms Williams. Despite admitting there had been no assessment of capacity in respect of contact she said her Operations Manager, Samantha Kilia, made the decision that as TQ’s role as a carer had come to an end and **she was not a relative it was “a nonsense to say she could visit”**. She supported her manager’s decision. She was
> asked how that policy decision placed P at the centre of a best interests decision and responded it was a **safeguarding risk**. **She said she and her manager assessed**
> **her as being a risk “because she is not a relative”**. Although she was aware TQ had taken him on holiday she did not regard that as altering the fact her role was professional and had come to an end.[17]

If relational autonomy is to be realised, appropriate relationships must actually be allowed to flourish, and not stymied by blinkered following of low-level policy and nonsensical

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[17] A (fact-finding) [2019] EWCOP 58

assumptions. It may be of use to consider concepts around boundaries, professionalism, friendship, vulnerability, power imbalances, and so on, in the light of this CoP ruling. The CoP has no jurisdiction in Scotland, but a case like this is likely to be influential and in any case it illustrates the general point that important relationships are taken seriously by the courts and that there is no obstacle in law (in either England or Scotland) to a professional carer and a cared-for person forming a meaningful friendship or having that friendship extend beyond the boundaries of their professional association. There is often a false belief that 'safeguarding' prohibits such meaningful relationships, but this is a harmful misconception[18]

But isn't SDM very unsafe? We can't just let supported individuals do whatever they want. They'd be dead in a week. Or arrested. Or beaten up.

There are of course limits to what individuals should be supported to do. We have already talked about one limit - supported individuals may only make those decisions that are theirs to make in the first place. But there are other limits to autonomy as well. Just like everyone else, supported individuals are subject to the criminal law. Supporting supported individuals to commit crimes is clearly not required. The other main limit is balancing human rights. The right of a supported individual to live the life they want may be restricted if it endangers their own rights, say the right to life, or the rights of others and that outweighs the person's other rights (to freedom of expression for example). In the words of Mary Condell, a lawyer who worked on the Assisted Decision-Making (Capacity) Act 2015 in the Republic of Ireland:

> the legislation is not just about 'the relevant person's' rights, it is about balancing and prioritising 'the relevant person's' rights against the similar rights of everyone else, whilst realising that systems have rules, not 'rights'
> [...]
> My final cornerstone comes from my experience with a woman who asked me, after she had listened to a presentation I gave on the 2015 Act, 'whether it meant that her mother had the right to expect her to stay at home and look after her'. I promptly replied 'absolutely no, that she herself has her own right to make decisions for herself about how she wants to live her life'. The 2015 Act is (quite rightly) described as 'rights-based'. Its purpose is to ensure that the rights of 'relevant persons' are respected and honoured. It does not mean, however, that the rights of those people who surround a relevant person do not also have to be taken into account and balanced against those of the relevant person.[19]

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[18] Williams, Paul (2021) 'The cold comfort of safeguarding', *Community Living*, vol. 35, no. 1

[19] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision-Making (Capacity) Act 2015", from *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (2021)

Part of supported decision-making is making rights-based risk assessments which considers all the relevant rights of everyone in a situation. It is important to distinguish between the severity of a risk, such as death and serious injury, and the likelihood of that outcome occurring. The principle of proportionality requires balancing both of these. So, for example, the potential risk of catching and dying from a serious illness (such as Covid) is a severe outcome, but may have a variable probability of occurring, depending on the current prevalence and precautions taken. On the other hand, if a person's family are not allowed to visit their home (in order to keep them safe from illness), that is a *certainty* of infringing the person's right to family life, with a seriousness which is affected by the length of time for which the exclusion persists. Death may be more serious than not having contact with family, but how likely is each outcome? A point will be reached at which the certainty of prolonged separation from family is a greater harm than the risk of death. That is positive risk taking. And it applies just as much to other areas of potential emotional and social gains, including having autonomy, when balanced against potential physical risks, which are usually the pre-occupation of services.

OK, but even within these limits, supported individuals will do a lot of foolish things that are not in their interests and which may even result in some harm. Do we just let them do those?

Quite possibly, if they fall short of the limits which would justify intervention. But consider that support workers, or even Decision Supporters (as provided for in the Irish 2015 Act and are being proposed for Scotland in the current review) are not advocates. They do not have to remain wholly neutral, and may offer advice and guidance to supported individuals according to their judgement, and if they have the trust of the supported individual may very well be able to support an individual to help them realise their goals most effectively and safely.

It is also important to consider the value of experience. We have all learned some of the most valuable and rewarding lessons from making mistakes. Invoking Blake again:

> *If the fool would persist in his folly he would become wise.*

The principle of allowing 'unwise' decisions is explicit in other jurisdictions such as England and the Republic of Ireland, and it is present in Scottish statutory guidance. Consider the Scottish Government's 2008 guidance on the 2000 Act, Communication and Assessing Capacity, A guide for social work and health care staff[20] pg 4:

> A person is not to be treated as unable to make a decision merely

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[20] https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2008/02/adults-incapacity-scotland-act-2000-communication-assessing-capacity-guide-social-work-health-care-staff/documents/0055759-pdf/0055759-pdf/govscot:document/0055759.pdf

> because he/she makes an eccentric/unusual or unwise decision.
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> (5) Presented with similar circumstances many of us will make different decisions because we give greater weight to some factors rather than others. Factors influencing our decisions will be our own values, preferences and previous experiences. Some people are keener to express their own individuality or more willing to take risks than others.
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> However, there may be cause for concern if an individual repeatedly makes unwise decisions and place him/her at significant risk of harm or serious exploitation. Concern may be triggered if a person makes a particular decision which defies all notions of rationality and/or is markedly out of character. In these situations it would be relevant to look at the person's past decisions and choices. While such situations should not automatically lead to the conclusion that capacity is lacking, they might raise doubts about capacity and indicate the need for further investigation.

Consider also that an obligation to develop decision-making skills is explicitly present in s 1 (5) of the 2000 Act:

> (5)Any guardian, continuing attorney, welfare attorney or manager of an establishment exercising functions under this Act or under any order of the sheriff in relation to an adult **shall**, in so far as it is reasonable and practicable to do so, encourage the adult to exercise whatever skills he has concerning his property, financial affairs or personal welfare, as the case may be, and **to develop new such skills**.

Making mistakes and being exposed to the consequences of them is one way to acquire such skills and knowledge. By 'consequences' we mean *natural* consequences, of course, not artificial consequences imposed as punishments, which obviously have no place in support services.

On decision-making as a skill to be learned:

> Would anybody have ever learned how to ride a bike without adequate support and a few failed attempts or falls? Stabilisers might be required for some time as well as someone to teach us or hold the bike, all with the purpose of one day being able to cycle without assistance and gain mastery of the new skill. It is no different for decision-making.[21]

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[21] Joanne Condon, 'Advocacy and the Assisted Decision-Making (Capacity) Act 2015'

Consider also the Mental Welfare Commission's 2021 Supported Decision Making - Good Practice Guide:

> 5.2.9 Allow for risk taking
> Risk taking is an important aspect of decision-making. In general, an adult should be entitled to take risks and learn from the consequences of them. In supporting a person, supporters may need to explain the nature and consequence of any potential risk to the individual. However, people have the right to learn from experience, to revisit decisions and change their minds and make decisions that others do not agree with.

On risk aversion with regard to people with intellectual disability and sex (possibly a topic for further separate work):

> Historically, services have struggled with supporting the choices of adults that were considered 'unwise' or 'risky': 'Where choices have been available between facilitating
> the sexuality of people with ID *[intellectual disability]* and protecting them from unwanted sexual encounters, services have typically sought to prioritise protection over empowerment'. (Keywood and Flynn, 2003). **This has often resulted in individuals with ID leading safe but lonely and isolated lives.** [22]

Autistic people are typically a more vulnerable group, and this may lead to support being very cautious and overprotective. It is important to make a distinction between vulnerability and weakness. While it is important to protect vulnerable people from abuse, this is not the same thing as protecting them from the normal, and valuable, run of physical, intellectual and emotional difficulty and pain that a full lived life entails. Difficulty is essential to development, and (if we accept the principles above) supported individuals should not be shepherded away from it.

> *The road of excess leads to the palace of wisdom.*[23]

From a service provision perspective, incidents are typically considered bad things, to be avoided, if for no other reason than the paperwork. This analysis suggests that there is a need to consider the potential benefits of mistakes and 'incidents' and the possibility that some re-evaluation may be required to see (at least some) incidents within care services as indications of positive risk taking leading to a rich life for supported individuals with ample opportunities to learn and develop.

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[22] Niamh Holland, *Responding to a Couple's Request for Support with their Relationship*, from *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 135

[23] William Blake, *The Marriage of Heaven and Hell*

Consider the following impassioned appeals from Adam Harris of AsIAm:

> And just because the person may make a decision differently to other people, or may approach the decision differently, that their decision is invalid, or that they shouldn't be allowed to make decisions, or that they should be protected from the world. Autistic people should be allowed, and supported, to have the same experiences as everyone else and to make the same mistakes as everyone else….
>
> …Can you imagine what life would be like without risks? Without unwise decisions? Without doing crazy, impulsive things? These decisions can be what makes life interesting. But when we talk about autistic people and other disabled people, we forget that people actually want to live their lives and do things, and not just attend services, designed by someone else, until they are elderly. And this is how it has played out for so many people, and that cannot be allowed to continue. Hopefully the 2015 Act can change this and allow people to take risks, and to live the life they want to live.[24]

But sometimes people contradict themselves. What if they say they want two things that can't both happen? People don't always make sense. Sometimes they simply can't tell us what they want, and there's no way to tell. We must make substituted decisions then, mustn't we?

If we can't, despite our best efforts, get a coherent position from a supported individual, it may at times be necessary to make a decision on their behalf. But making a decision **on behalf of** the supported individual is not the same thing as making a decision based on what *somebody else* thinks is good for them.

Consider the following:

> An autistic man, Arthur, wants to be discharged from hospital. But he cannot be until a suitable bed has been installed in his home to prevent very serious risk of physical harm which would likely breach his rights to life. But, whenever he is asked, he says he does not want a special bed to be installed in his home. That means he can't be discharged from hospital. So, he both wants to go home, and doesn't want to have a new bed installed, and these two preferences are in conflict - doing both is impossible.
>
> A skilled Best Interests' Assessor, highly trained in the principles of the Mental Capacity Act (the English law which applies) consults thoroughly with Arthur's friends as well as professionals involved. She recognises that, in this situation, Arthur's

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[24] Adam Harris, 'Living with Autism: the Contribution of the Assisted Decision-Making (Capacity) Act 2015'

> overall autonomy would be best served by installing the bed in his house, even though he says he doesn't want this. It is apparent to friends who know him well that his overriding desire is to be at home and that he would probably get used to the new bed in time. He would be happier at home overall and have more control over his life at home. In this particular situation, making a substituted decision **on his behalf** after a finding of mental incapacity (with respect to this decision alone) was the best way to uphold his autonomy overall.

This type of decision is based on an interpretation of what we think Arthur would probably choose, if only he was able to think it through clearly, and draws strongly on knowledge of the individual concerned. Arthur's will and preferences are still determining the decision, even though he is not quite able to make the decision himself.

Scottish mental capacity law is a little behind at present with explicitly saying that all assessments of mental capacity should be made on a decision-by-decision basis, and capacity should be presumed. England and the Republic of Ireland both have this principle explicit in law now, and Scotland has it in guidance. The current review of mental health and capacity law in Scotland includes it in their proposals. It is hard to imagine the reformed law will not include this principle.

Under circumstances when we cannot adequately determine what someone's will and preferences are, even after strenuous effort, it may be consistent with promoting autonomy to make a **best-interpretation decision**, that is to say, a best guess as to what that person *would* choose, if they were able to. For social care workers to be able to do that requires a strong relationship with a supported individual, of the kind already described. Mary Condell again:

> …always assume that everyone is capable of being supported to make decisions about
> themselves for themselves, and if they patently cannot (for example, if they are in a coma), still honour their right as a human being to self-determine by finding out what they would want for themselves in these particular circumstances[25]

If staff make friends with supported individuals, and earn their trust, won't that give them a lot of power in a relationship with a vulnerable person?

Absolutely, of course it will. But not all influence is undue influence. While close relationships carry a risk of undue influence, and emotional hurt and distress, these are normal parts of life for everyone, and an inevitable consequence of close relationships. There is no reason

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[25] Mary Condell, "Personal Reflections as a Lawyer on Experiences with the Assisted Decision-Making (Capacity) Act 2015", from *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (2021) p 218

why a supported individual should be spared this facet of life, if its absence would mean isolation, loneliness, and diminished autonomy.

There may be sources of strong, perhaps undue influence in a person's life. There may be a domineering relative, guardian, friend, support worker, manager, psychiatrist. Perhaps the sources of undue influence are not personal but institutional, at the level of policy or culture. Close staff members may be ideally positioned to not only notice these but also be willing to act to protect individuals from such undue influence. Such risks can be minimised by encouraging multiple formal and informal relationships, such as a circle of support[26]

A significant risk to supported individuals' autonomy and a barrier to developing trusting relationships are conflicts of interest. Staff in care services are, typically, not actually answerable to supported individuals in any formal way. Even if a supported individual makes a complaint about a service, that complaint is then handled and resolved by others. Supported individuals cannot sack staff. It is a consequence of this structure that staff may be more focussed on the priorities of their line managers, the Scottish Social Services Council, the Care Inspectorate and local authority commissioners, than on the priorities of the individual they are supporting. It is very difficult for an individual to develop trust in a staff member who will prioritise everyone else's will before the will of the individual.

But if I start doing supported decision making, and making friends with supported individuals, and no-one else does, I'll stick out like a sore thumb. This is not going to be fun. I can't really do this in the culture I work in. A lot would need to change first.

Culture change has been commented on in the literature. In the context of the Republic of Ireland's recent reform of their mental capacity law, the prospect of culture change has been called a 'hurtling train' coming towards the health and social care system.

> "…the cultural norms around decisions are learned and reinforced by employers through policies and procedures and by managers and colleagues on a daily basis.
>
> Yet these cultural norms are about to be challenged – significantly.
>
> It seems to me, as a manager in the health services, with 25 years of health and social care practice (in social care, social work and administrative management across various sectors and two countries) that Ireland is in a very early phase of major change and transition to a rights-based approach. It is really in the pre-implementation phase. That is, most staff are not fully aware of the train that is hurtling towards them." [27]

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[26] https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/c/circles-support-and-circles-friends

[27] Gerry Maley, 'Best Interests and the Transition to a Rights-Based Approach in Irish Health and Social Care'

The principles of the Adults with Incapacity (Scotland) Act 2000 appear to have had little impact in 22 years on the broadly paternalistic culture that seems common in social care services in Scotland. It is to be hoped that the forthcoming reforms will be rather more far reaching in challenging existing culture and rooting care and support in principles designed to support autonomy. However, legislative change cannot bring about culture change entirely by itself. For example, in England following the commencement of the Mental Capacity Act, The House of Lords Post-Legislative Scrutiny Report highlighted (emphasis added) that:

> "...the 2005 Act has suffered from a lack of awareness and a lack of understanding and failed to achieve the cultural shift required, stating **'for many who are expected to comply with the Act it appears to be an optional add-on...' and that 'the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded.'**[28]

It is likely that, in addition to legislative changes, genuine culture change within care and support organisations requires changes (perhaps structural) to ensure accountability to supported individuals, who are the people it exists to serve.

I'm very uneasy about me being 'friends' with supported individuals. I don't restrain my friends. That would be awful and totally inappropriate, unless they were drunk or something and about to walk in front of a car. If I make friends with supported individuals, but then I have to suddenly become all professional and restrain them and control them, won't that completely destroy trust?

Quite possibly, yes. Looking seriously at relational autonomy and the critical importance of building relationships of trust inevitably requires reflection and reconsideration around policies on restraint and any culture of control.

But we have to prompt people. If we don't get supported individuals to do things, they'll never do anything.

Prompting is not the same thing as taking away choice and control. Prompting is critical to helping autistic people do the things they want/need to do. Prompting is good as long as that person wants and needs those prompts in order to maximise their overall autonomy. As we all know, autistic people can have great difficulty getting things done, even things they want to do. Sometimes this is called inertia. Inertia is well known among the community of autistic people and is now the subject of groundbreaking research[29].

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[28] https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm

[29] Buckle, K. L., Leadbitter, K., Poliakoff, E. and Gowen, E (2021) "No Way Out Except From External Intervention": First-Hand Accounts of Autistic Inertia, Front. Psychol., 13 July 2021 | https://doi.org/10.3389/fpsyg.2021.631596

But SDM is impractical. If we did it with every decision, we'd drive the supported individual crazy! We'd never get anything done; we'd spend all day trying to extract decisions from them.

Consulting someone over every single decision made in a day might indeed be impractical and counter-productive for everyone, although some supported individuals might want a level of fine-grained control depending on the context. Other individuals will find the social interaction involved in supporting them to make many decisions to be totally overwhelming. Asking someone what they want to do all the time might lead to chronic overload, perhaps resulting in a shut-down or a melt-down, in which they cannot make any decisions at all. Sometimes, the best way to support someone is to leave them alone. One way around this problem is to support a supported individual to make strategic decisions which are revisited from time to time. For example, a supported individual might decide how they want their room to be arranged. Then, if a support worker has to move anything, they know where to put it back without having to ask the supported individual every single time. If a supported individual, perhaps with support, decides a weekly routine, then the staff can follow that without having to ask the supported individual every day what they should be doing. Many of these higher-level decisions about **systems** and **routines** can and should be recorded in a **support plan**. Which brings us to the next issue.

But staff have to follow the support plan, not what the supported individual says they want. Commissioners expect our staff to follow the support plan and they are the ones funding the support.

It is important to reflect on potential conflicts between what the supported individual wants to do, and what is written in the support plan. If there is such a conflict, then that should be taken as an indication that the support plan needs to be revised to ensure that it meets the supported individual's needs in ways that work for them and are consistent with their wishes and preferences. It is likely to be useful to regularly ask staff who work directly with supported individuals whether they ever feel conflicted and uncomfortable and/or whether they ever encounter situations in which there is a conflict between what they believe the supported individual wants and what the support plan, or a manager, or a colleague, tells them to do. Joe Long found that:

> "The staff workshops and practitioner resources that we convened to disseminate research findings emphasised the need for **authenticity of voice over third person authorship in service documents**; the use of media that were meaningful to the individual, rather than a reliance on written documentation; ownership of the process of producing supports; concrete outputs from choice-making activities to refer to and support self-advocacy; and a shared understanding of choices made between individuals, their families, and support staff (Long et al. 2017, 12–13)."

The support plan is the obvious place where strategic decisions can be thought about, discussed, and ***made by*** the supported individual (not ***made for*** the supported individual) and recorded. To the extent that support plans determine what happens in a service, a person's autonomy is promoted or thwarted to that same extent. A support plan could be either a mechanism for promoting autonomy, or an accidental means of oppression, depending on who controls it.

(NB - for the avoidance of misunderstanding, the way to avoid 'third person authorship' of a document is NOT to use 'I' statements which are written by anyone other than the supported individual themselves. Expressing the views of staff, family members or anyone else as if they were the views of the person themselves is poor practice and fundamentally at odds with SDM. Where a third person, such as staff or family members, has to do the writing/typing for whatever reason, that must be transparent. If a supported individual is able to express their view in words, then their actual words should be included in quotes.)

Within care services, support plans can function as a way for the organisation to communicate expected actions to staff and exert control over those actions. Where support plans are used, explicitly or implicitly, in this way, it can result in support plans being drawn up by staff and managers with relatively little direct input from supported individuals. A potential route to addressing this is to make structural and procedural changes to place the ownership of the support plan much more firmly in the hands of the supported individual. While the use of some type of support plan is inevitable within formal care and support services, it is critical to the autonomy of supported individuals that their will and preferences are given effect in the support plan and that the degree to which this is the case is reviewed regularly. This may require the involvement of an advocate or other independent person (such as a 'decision supporter' if such a role is created in legal reforms) with the skills to challenge staff and family perspectives as necessary. Other approaches which are relevant to ensuring the support plan is meaningfully owned by the supported individual and gives practical effect to their wishes and preferences over those of staff/family/organisation might also be explored.

This also requires that support plans must be accessible to the supported individual, both in terms of where it is stored and how and when a supported individual has access to it, as well as the format of the plan itself. If the support plan stored in a location the supported individual does not have ready access to, it may inadvertently signal that a supported individual's life does not really belong to them. The format of support plans is also important and should be accessible, perhaps as easy-read versions, or in other formats as Long suggests. This would enable supported individuals to remind themselves of what the service provider has agreed to, hold staff accountable and more easily indicate if they are no longer happy with something in the plan. If the support plan is an accessible tool for the supported individual to have control over their support, rather than a document expressing organisational or managerial intent, this would significantly increase a supported individual's control/governance over their life as a whole

This may require uncomfortable consideration of what the support plan actually is. Is the support plan the same thing as the will of the supported individual? To the extent that it is, a supported individual's will may override the written plan, which becomes out-of-date the moment a supported individual changes their mind. However, a supported individual may also wish their strategic level decisions not to be overridden by their own immediate responses (especially to spoken questions) and this should also be respected. Staff would need to have the confidence and skills to make judgements about when to follow the written plan, and when to think "Ah, what the supported individual is saying should take precedence over the written plan in this instance." These might seem like very abstract philosophical questions, but it may well be worth giving careful consideration to what a support plan is, where it exists, and exactly the relationship between it and the will of the supported individual.

But some people find choice overwhelming. One reason we make decisions for people is so they feel secure and not overwhelmed with uncertainty and responsibility that they can't understand and can't cope with.

Yes, decision-making can be very stressful and quickly use up a person's supply of spoons.[30] This is further evidence of the importance of supported individuals having broad strategic control of their lives, and over their support plan, in whatever ways they are able to manage, so they don't get overloaded with a million little decisions.

But what if it does go wrong and a supported individual comes to harm? Won't staff get into trouble?

It is clearly important for staff and managers to know where they stand in terms of their own risk so that they can work confidently without fear. More work needs to be done on this to ensure staff and managers at all levels of service provision have a good understanding of the limitations of liability and the legal foundation of positive risk taking. The Adults with Incapacity Act 2000 contains an explicit limitation in s 82 (emphasis added):

> 82 Limitation of liability
> (1) No liability shall be incurred by a guardian, a continuing attorney, a welfare attorney, a person authorised under an intervention order, a withdrawer or the managers of an establishment for **any breach of any duty of care** or fiduciary duty owed to the adult if he has or they have—
> (i) acted reasonably and in good faith and in accordance with the general principles set out in section 1; or
> (ii) failed to act and the failure was reasonable and in good faith and in accordance with the said general principles.

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[30] https://www.edpsyched.co.uk/blog/autism-spoon-theory

This is an expression of the broader public law reality that duty of care requires only decisions which are not negligent, rather than the elimination of all risk. The importance of work to combat significant fear of liability at all levels of staff should not be underestimated. This is a challenge in common across all care organisations. Staff can be greatly hampered in delivering good practice where they have a persistent, though unfounded, fear of being liable (both legally and in terms of blame within an organisation) if 'something bad happens'. This fear exists at all levels of staff within care organisations, based usually on misconceptions of Health and Safety rules and duty of care. Gerry Maley outlines the prevalence of this culture of fear and blame:

> "Also, whilst the HSE's Incident Management Framework 2020 outlines the positives of promotion of a 'just culture' and the risks involved in a 'blame culture', the writer's experience is that many staff feel the sword of Damocles of the latter – perhaps less recently within the HSE, but mention is still heard of the courts or external inquiries, statutory or otherwise, which are not regarded as learning opportunities or reflective experiences; they are expressed in terms relating to fear and threat. This remains unhelpful." [31]

But we already ask supported individuals what they want and they don't say anything. They don't even *want* to make their own decisions.

Some people are so used to having decisions made for them that they struggle to even grasp that they are allowed to take some control of their lives. This can be the case where people continue to be treated as children even after they have grown up (infantilisation). Consider this comment from one of the supported individuals in the Australian SDM Project after they had begun to appreciate the benefits:

> 'My feelings are angry. I don't want to be there. Maybe there will be light at the end of the tunnel. I feel free when I talk to... (his supporter). I feel a little bit scared because my
> [family] will be upset if my decisions work [for me]. My brain tells me I am a man... they
> think I am a baby.'

It can also happen when a person has been in a service for a long time and has got used to decisions being made for them all the time (institutionalisation). Consider another comment from a supported individual in the South Australian SDM project:

> '[I] feel confident. [I] get confidence from having people believe I
> could do [these things]. A large percentage of people didn't expect me to

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[31] Gerry Maley, 'Best Interests and the Transition to a Rights-Based Approach in Irish Health and Social Care'

> survive, didn't recognise [that I could]. One said six weeks and you'll be back. That was nearly a year ago.'

This fact has been recognised by the Court of Protection in England in case about where a supported individual (ZK) with impaired capacity should live[32]. The details of the case are not especially relevant, but a comment from Dr O Rourke, who assessed the capacity of ZK is very interesting and relevant to SDM (emphasis added):

> I am not suggesting that he is currently subject to undue influence or pressure, although he is aware of being in the middle of a dispute about where he should live. My comments reflect that, **in order to make a decision, first one needs to be aware that one is in a position to make a decision.** [ZK] has only recently begun to make very small decisions and assert his needs and is used to others telling him what to do. He does not experience himself as having agency and my concern is any 'decision' made by him would be a response to what he perceives others to want, rather than a consideration of what he himself would prefer.[33]

This highlights a very important step in the realisation of autonomy. For some decisions, before an adult can make their own decision, they first need to understand that they **can** and **may** make autonomous decisions. Typically developing people usually acquire this sense of *agency* gradually as they grow up. But often disabled people, particularly those with intellectual disabilities and/or autism, have not been given opportunities and support to develop this. If an adult doesn't experience the opportunities and support to realise that they are an autonomous adult and develop the confidence to make their own decisions, they are likely to just go along with what others think they may want. This suggests that increasing the control of supported individual's over their own lives requires consideration of how to develop a supported individual's sense of being an *agent*, with the ability and power to make their own decisions.

From assessing capacity to building capacity

There is commentary in the literature, especially from the Republic of Ireland, on a change of perspective. Traditionally capacity assessments are made in order to determine if an intervention may be made. It's a judgement about somebody, and if the person fails the test their legal capacity gets taken away, and substituted decisions follow. There is now recognition that this is a very negative way to approach capacity and not at all consistent with the CRPD. It is now widely recognised that, instead, the first thought should be "How do we support this person to be able to make a decision?" Consider the following extracts:

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[32] Re ZK (No.2) [2021] EWCOP 61

[33] [2021] EWCOP 61 between A LOCAL AUTHORITY - and - ZK (by his litigation friend, the Official Solicitor) -and- SB

> “The 2015 Act will mean a role reversal for us health professionals from capacity assessor to capacity enhancer.” [34]

And this from lawyer Mary Condell again (emphasis added):

> “I ask people to imagine, that as someone gradually becomes unable to make all decisions without support, they enter a tunnel which, naturally enough, becomes darker the further in they go. A professional is not facilitating a ‘relevant person’s’ capacity by standing at the mouth of the tunnel and calling upon the relevant person to come and engage with them there. This is the old status approach where a ‘relevant person’ was marked down or defined by what they cannot do compared to a ‘normal’ person, as in for example the Mini-Mental State Examination (MMSE). Facilitating a ‘relevant person’s’ capacity is the direct opposite to this. It requires the decision supporter to enter the tunnel themselves, locate where the relevant person is, stay there with them and communicate and work with them in their space in order to find and then **enhance whatever decision-making ability they have**. It is this difference in approach, which necessitates a **complete change of culture** that is causing tensions amongst doctors and other professionals.” [35]

Lessons from experience: Top tips from St Michael’s House

The following reflections echo some of what has been said so far and are a valuable insight from a professional service who has already gone some way to implementing SDM practice in their service. We therefore quote in full the conclusion of the article ‘Supporting Adults with an Intellectual Disability to Make Decisions: Reflections from an Organisational Perspective’ by Elaine Teague:[36]

> So, now that we are one year on from the establishment of the ADM Steering group and
> using implementation science to guide us, what have we learned?
>
> **Start and Get Better**

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[34] Seamus Moran, ‘Social Work as Partnership’, from *The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections* (2021)

[35] Mary Condell, “Personal Reflections as a Lawyer on Experiences with the Assisted Decision-Making (Capacity) Act 2015”, from The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections (2021)

[36] The Assisted Decision-Making (Capacity) Act 2015: Personal and Professional Reflections (2021) p 127

The feeling of not knowing where to start can be paralysing – sometimes it's easier to do
nothing than start. Waiting for the 2015 Act to fully commence, waiting for case law to emerge, waiting for Supreme Court judgments, not having enough resources, being busy with other matters are all reasons not to get started. However, by starting, you learn what is needed. There is no such thing as the perfect time to get started – start slowly and get better over time!

Include the adults who use the service
By including adults who use the service to help guide the key messages and priority areas, it lessens the risk that it becomes a bureaucratic exercise. Service users keep us focused. They know what is important to them and it is our role to respond to that.

Don't overcomplicate it
Look at what you have in place – what can be useful to you? By using existing structures, you can reassure people that not everything will change. Pick a few key things to focus on and communicate those. We identified two key messages:
- *Will and preference instead of best interest*
- *Build capacity rather than assess capacity*

Culture eats strategy for breakfast
Culture is 'how we do business around here' – we learned that if you start with the willing
(those who are already committed to a rights-based approach) you can win the hearts and minds of others. There will always be people who do not think ADM [assisted decision-making] is necessary. Do not focus on convincing them – save your resources for those who are open to being convinced. Building case examples, one person at a time, one decision at a time can help to shift culture and show people the alternative way. It also allows the organisation to learn what is needed (e.g. policy updates/coaching for staff, etc.)

APPENDIX 1 - The South Australian Supported Decision Making Project

One well documented project was conducted in South Australia and the Final Report published in 2012.[37] According to the Final Report, it went very well (our bold):

> "The Supported Decision Making project has demonstrated that there were specific benefits to most of the participants. These were seen in their **increased confidence** in themselves and in their decision making. There was evidence of **improvement in decision making skills**. Participants described the growth in their support networks. Many reported that they felt **more in control** of their lives. Participants gave evidence that they had **increased their engagement** with the community, either through expanding their options or through making decisions that changed their circumstances.
>
> The evaluation gives evidence that Supported Decision Making was both a companion process and **viable alternative to substitute decision making** for participants who were initially on Guardianship Orders." (pg 4-5)

The arrangement was as follows:

Trialled with 26 people as a proposed replacement for Guardianship. Not all those included in the trial had a guardian. The mechanism is an 'SDM Agreement.' The supported person 'chooses' someone to be their supporter to 'assist me to make decisions'. The decision supporter is authorised to support with high-level decisions such as where to live as well as lower level decisions. In practicing SDM, the decision supporter helps by:

> "Providing information in a way I can understand.
> Discussing the good things and the bad things that could happen.
> Expressing my wishes to other people"

Where they make decisions which a Guardian is authorised to make, the Guardian retains final responsibility for these, however the Guardian agrees to take into account the SDM decision when making their final decision.

What did the supported individuals think of it?

> Johnny:
> '[I] feel confident. [I] get confidence from having people believe I could do [these things]. A large percentage of people didn't expect me to survive, didn't recognise [that I could]. One said six weeks and you'll be back. That was nearly a year ago.' (pg 19)

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[37] http://www.opa.sa.gov.au/files/batch1376447055_final_supported_decision_making_evaluation.pdf

Kathleen and her supporter believe that using Supported Decision Making 'helps to make things clearer', 'gives me a little bit of security about what to do,' 'helps me be the person I want [to be]' and does 'support decision making.' Kathleen said that she tried writing down her decisions, but did not use the project diary. She said that now she 'thinks about it before saying Yes.' (pg 25)

'I am more independent - I talk about [things] more.'

'I set my goals.'

'I sent an email looking for an explanation about... The explanation made me feel better.'

'I have confidence to make decisions, even if [it is a] mistake.'

'It made me think before I do. Now I think, what do I want this for.'

'I have learned to say no. I am happier ...'

'My kids have noticed a big difference in me. [My daughter] said she is so proud of me. It
made me cry.'

'I get my independence. I think for myself - I feel good about making decisions. It's my new life. [I have] confidence in myself that I never had before. I didn't used to speak my opinions.'

'Now I do my own shopping, look after myself. I am feeling good. Not as depressed.'

'I go to [the] problem now, take advice. I'm thinking properly for myself. Life's not too hard. There are people who can help me, and sometimes you've got to ask for help.' (pg 31-32)

'My feelings are angry. I don't want to be there. Maybe there will be light at the end of the tunnel. I feel free when I talk to... (his supporter). I feel a little bit scared because my
[family] will be upset if my decisions work [for me]. My brain tells me I am a man... they
think I am a baby.' (pg 33)

What did the families and friends of the supported individuals think of it?

Johnny's sister said that his involvement in the project 'saved his life and made his life worth living again as he was his own boss.' His friends thought that Johnny had achieved a level of happiness in the last eighteen months of his life. (pg 19)

'I see her differently. I let her go.'

'It is important to consult [her] about holidays, as opposed to believing her capacity to decide is conditioned by communication, as [she] is non-verbal.' (pg 36)

What did the decision-supporters think of it?

'She is more opinionated about what she wants to do. I really enjoy that.'

'I can see [he] has got stronger.'

'has made a lot of difference. He can run [his] house on his own and pay bills now.' (pg 35)

'I am a trusted friend, not a carer.'

'They communicate with me, are concerned for me.'

'We feel OK about going on [as supporters]. We have a friendship that will last. We love him.' (pg 35)

What did the professionals think of it?

Staff members from the state government disability agency saw benefits in the Supported Decision Making process …. The particular strength of the process from their point of view was that the SDM Agreement gave the participant 'formal approval, a piece of paper, that said somebody is going to listen to me... it restores power.' (pg 38)

The SDM Agreements were seen as having real advantages. They gave legitimacy to the participants to express their views and have conversations. The process underpinning the SDM Agreements also allowed for conversations that would not have otherwise occurred. One of the staff members from the agency said that 'it gives permission and opens up an opportunity ... to start with the person and to be more personal. We can exchange information.' (pg 39)