Supported Decision-Making
A Framework

Developed by People First (Scotland)

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Foreword:

Most people in our communities believe that, at best, we are "poor souls" needing looked after and, at worst, that we are a nuisance and a drain on society and that we are somehow dangerous and unpredictable.

Our lives are ruled and directed by laws and policies that we have had no say in. To make matters worse, the discrimination we face in daily life is reflected in the laws of this country. Instead of seeing us as citizens who happen to take longer to understand things and who need more time to learn and who might need supports to do some things, we are often presented as very different from other human beings. This has been true through most of history and has been the excuse offered up when we have been sent to concentration camps, sterilised, disposed of or placed in institutions.

The significant, and increasing, use of substitute decision-making in relation to people with an intellectual impairment is of significant concern to People First (Scotland).

People First (Scotland) has been campaigning for many years to remove 'learning disability' from the label of mental disorder. This is because an intellectual impairment is not the same as a mental health condition. An intellectual impairment cannot be 'cured' or even 'treated', and there is never any time when we do not have our impairment. It is always there. In addition, we argue that our life experiences, as persons with an intellectual impairment differ considerably to those who have mental ill health or cognitive impairments through an acquired brain injury or dementia. Our different life experiences impact on our ability to make decisions at least as much as our intellectual impairment.

Most people in society learn from an early age to express a preference, to consider consequences and to become autonomous. This is most often not the case for those of us with an intellectual impairment. That is why this framework for supported decision-making is intended for people with intellectual impairments, their families, their supporters, professionals and anyone else taking an interest in improving the lives of people with intellectual impairments living in Scotland. Other groups are welcome to use any part of the framework they think will work for their conditions.

As an organisation run by, and for, people with an intellectual impairment, People First (Scotland) believes the views of people with an intellectual impairment themselves should be central in working out how they should be supported to make decisions. This framework for supported decision-making has been developed by the Law and Human Rights group of People First (Scotland).

Fiona Wallace

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People First (Scotland)

Introduction and Aims

People First (Scotland) is a user-led membership organisation of people with learning disabilities. Our focus, in developing this framework, is on how it could work for people with learning disabilities, even though we know that other groups have an interest in supported decision-making. In this document, we use the term "intellectual impairment" to refer to people with learning disabilities because we know this debate is happening across the world and we think "intellectual impairment" will be understood better by disabled persons' organisations in other countries.

Information from the Mental Welfare Commission Scotland confirms that in 2014-2015 a total of 1,177 applications were made for Guardianship orders for adults with an intellectual impairment. Only two out of those applications were not approved although we know that in both of those cases the Guardianship process went ahead anyway with different people named as Guardians. That means 100% of the applications were granted. Guardianships went ahead and all 1,117 people lost the right to make their own decisions about their own lives.

Guardianship applications for adults with intellectual impairments are rising at alarming rates, with reported trends of parents being encouraged to start applying for these orders before their children have reached the age of 16. This means that more and more people with intellectual impairments are having their right to make decisions about their own lives taken away from them. The Mental Welfare Commission's Report on Adults with Incapacity 2015-16 provides more information on this.

Although the Adults with Incapacity (Scotland) Act 2000 and the UN Convention Article 12 (Equal recognition for disabled people before the law) are not very far apart in theory, the way the Act has been applied for the last 17 years in respect of people with intellectual impairments has been entirely different both from what the Scottish Parliament intended when it was passed and from the intention of Article 12 of the UNCRPD.

People First (Scotland) entirely supports the idea of self-determination of people with intellectual impairments and supported decision-making is an obvious step in that direction. Equally, we recognise that there are challenges in the process, especially where the degree of intellectual impairment is very profound. Nevertheless, we believe it will be possible to construct a system where all people have the right to decide about their own lives and not have those rights removed from them.

Current Legal Context

In Scotland, the Adults with Incapacity (Scotland) Act 2000 (The Act) legislates interventions for adults that are assessed as lacking capacity, or want to make advance provisions for a period of impaired capacity. When the Act was initially introduced People First (Scotland) welcomed it, as the principles are based on the wishes of the adult, the least restrictive option and, crucially, a commitment to supporting the adult to continue to develop their skills with a view to remove guardianship orders once they are no longer needed.

Unfortunately, this is not how the Act or the principles have worked in practice. Instead of Guardianship being used as a 'last resort', the Mental Welfare commission reports large numbers of applications for adults with an intellectual impairment, and an increase with every year that goes by. These applications are seldom challenged and too often include welfare as well as financial powers, covering all aspects of decision-making. The Act's intent was that guardianship applications would be decision-specific and would last for the shortest amount of time possible, with a maximum of three years. However, guardianship orders are at times granted for an 'indefinite' period on the grounds that the intellectual impairment will be with the person for life.

In 2009 the United Kingdom ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This convention, which emphasises equal rights for persons with disabilities brought with it a paradigm shift towards a more human rights-based approach for persons with disabilities, cemented in a system of supported decision-making. Many countries, states and provinces across the world have introduced the concept of supported decision-making into their legal frameworks. There has, however, been very little work on the precise definition of supported decision-making and the limits (if any) of that process. This, in turn, has led to some scepticism about whether supporting decision-making of people who are intellectually impaired to varying degrees is a feasible and realistic proposition.

This Framework is our attempt at constructing a definition of supported decision-making while also providing a framework for practice.

We like the idea of Representation Agreements from British Columbia in Canada but with two major differences. Firstly, Representation Agreements exist alongside Guardianships as an alternative to them. This creates an uneasy relationship between the two and there are constant arguments between parties about which system should come into play. We propose in Scotland that Guardianships should not continue and that Supported decision-making should replace them. Secondly, we think the name of Representation agreements suggests the Representative is active in place of the person and we prefer the name Supported decision-making where the supporter works alongside the decision-maker who is in charge of their own decisions.

Article 12 of the UNCRPD is about equal recognition before the law. In the General Comment no.1 on Article 12, the UN committee confirms that it considers systems of substitute decision-making to be fundamentally incompatible with human rights legislation, particularly Article 12 of the United Nations Convention on the Rights of

Persons with Disabilities (CRPD). The UN Committee on the Rights of Persons with Disabilities has stated that:

> "a person's status as a person with a disability or the existence of an impairment... must never be grounds for denying legal capacity or any of the rights provided for in article 12."

This requires that "States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life", calling on states parties to abolish practices such as Guardianships and instead develop systems of supported decision-making that can be incorporated into law.

Article 12 - Equal recognition before the law

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

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

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

4. 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. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

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

Substitute decision-making does not, however, only exist in relation to the Adults with Incapacity Act. It can occur informally, in family relationships for example, or in professional settings. We recognise that this is predominantly done from a position of care and caring responsibility. Nonetheless, we are striving for a society where people with an intellectual impairment are treated as *equal citizens*, and where support systems enable rather than hinder this.

Deprivation of Liberty

In looking at the current legal context, we have to make some mention of deprivation of liberty. Ever since the "Cheshire West case" and the ruling of the Supreme Court[1] in 2014, and the earlier references by Sheriffs in Scotland[2] that where an adult has been assessed as lacking mental capacity to make decisions then the "least restrictive option" to avoid the adult facing deprivation of liberty is guardianship and a substitute decision-maker agreeing to the treatment and care arrangements of the adult. In this model, the legal remedy to the person having treatment or care to which they have not consented (on the grounds that they lack the capacity to consent) is to have another person consent on their behalf. In the supported decision-making model which we propose here, since there would be no loss of right to make decisions, regardless of degree of intellectual ability, there would be no need for a substitute decision-maker. The person him or herself would simply make their own decision about whether they agreed to the care and treatment with sometimes intensive support from a decision-supporter. Sometimes the person would agree and there would be no deprivation of liberty. Sometimes the person would not agree and, ideally, alternative arrangements should be made which are more suited to the person's preferences. Where the State decided that the person should remain in the place they were opposed to, the onus would be on the State to seek legal authority to deprive the person of their liberty but that case could not rest on the argument of mental incapacity.

A New way of thinking about legal capacity through supported decision-making

With the publishing of General comment no.1 on Article 12 came a focus on practices and policies of substitute decision-making. The general comment says:

> 'Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from substitute decision-making paradigm to one that is based on supported decision-making'.

Article 12 of the UNCRPD states that a person should never be denied their legal capacity, and it puts obligations on state parties to facilitate this change, from one paradigm to another. According to the UN Committee on the CRPD, 'Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where:

(i)   legal capacity is removed from a person, even if this is in respect of a single decision;

(ii)   a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and

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[1] The case of *P (by his litigation friend the Official Solicitor) (Appellant) v Cheshire West and Chester Council and another (Respondents)*; *P and Q (by their litigation friend, the Official Solicitor) (Appellants) v Surrey County Council (Respondent)* [2014] UKSC 19
[2] Sheriff Baird in *Muldoon, applicant* 2005 SLT (Sheriff Court) 52 and by Sheriff McDonald in *M, applicant* 2009 SLT (Sheriff Court) 185

(iii)   any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.

In contrast to this, supported decision-making involves carefully and skilfully providing support that enables people to make their own decisions. The United Nations Handbook for Parliamentarians states

> "With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when the person with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual."

What is supported decision-making?

Supported decision-making starts with the idea that everyone has the right to make their own decisions. It follows with the commitment to provide sufficient and effective support which compensates for any difficulties with decision making. People with intellectual impairments are supported to make all decisions, through changed expectations of others, development of their skills and experience, provision of support to express their will and preferences and, at times, through the interpretation of their will and preferences. In supported decision making, the person with intellectual impairment is at the centre of their own decision making:
• support is made available to enable the person to make decisions
• support is tailored to the person and their situation
• support varies in type and intensity depending on the type of decision
• supporters enable the person to exercise choice and control based on the person's will and preference (**not** perceived best interests)
• a person's legal capacity is not questioned because by definition it cannot be removed

It is our hope that a shift towards support for people with intellectual impairments to make their own decisions will not just be reflected in the law, however important that is. We expect there to be a fundamental attitudinal shift in the general population to see people with intellectual impairment, whatever the degree, as whole human beings and equal citizens. We expect that will, over time, change the behaviour of workers in care and support services as well as health and social care and education provision. We want to see efforts made to develop the ability of people with intellectual impairment from a very early age to have preferences and to be confident about expressing those and to understand that this is a right that all citizens have. By its very nature, the presence of an intellectual impairment may well make the process of developing that ability more difficult or take longer than for some other citizens but we believe it is a fundamental right of all people to be encouraged and supported in that process.

We further believe that, as this "paradigm shift" happens over time, more and more

people with intellectual impairments will have the ability to make many more decisions, with probably reduced need for support, than happens at the moment.

For the time being, though, it has been argued that there are forms of supported decision-making and self-determination already in Scots law. While it is true that the intent of the Adults with Incapacity Act is that it should only be used when no other supportive measures have been successful, this is not the way that it has been used in practice. The other argument that has been advanced by those who believe there should be no change is about **Advance Statements** under the Mental Health (Care and Treatment)(Scotland) Act 2003.

In Scotland, advance statements are a way in which people with a 'mental disorder' (defined by the Mental Health Act) can provide a means for a person to specify, prior to developing the assessed incapacity as a result of their mental disorder, what treatment they would prefer, and what not. As the decision-maker is the one who determines what is included in the advance statement, they have been hailed as good practice examples of supported decision-making. However, this is not the case for persons with an intellectual impairment. While it is true that a person with a mental illness, or prior to the onset of dementia or in anticipation of any other cognitive impairment, can make these statements, it is far too easy to ignore the advance statement by challenging the person's capacity at the time of drawing up the statement. Particularly for intellectual impairment, where the level of impairment is likely to be viewed as static. People with an intellectual impairment are therefore not offered the opportunity to draw up advance statements in the way that other members of society are.

In the same way, it has been argued that substitute decision-making happens under different laws in Scotland. Our view is that there is a very clear difference between a decision which is made by a substitute decision-maker on behalf of an individual who has been assessed as lacking capacity and a decision which is made about a person by someone who has been given the authority to act in that way for groups of people (such as some medical professionals and members of the judiciary). In the latter case, the psychiatrist or judge is not substituting for the person's own decision-making, they are simply arranging for the treatment (or punishment) that their role allows and requires them to do. Supported decision-making is presented as an alternative to substitute decision-making (Guardianship under the Adults with Incapacity (Scotland) Act 2000) and does not have a place where legal decisions are made about a person but not substituting for their own decision. It may well be that a person subject to those kinds of authority would need additional support, but it would not be supported decision-making.

Best Interests versus Will and Preference

In the legal and academic debates about the UN Convention, there is a great deal about the idea of "best interest decisions" made about the person by other people and the opposing idea of self-determination where the person's own "will and preferences" lead the decision-making process.

It is our view that this is basically a false distinction. When any person makes a decision, it is not true that they decide things which are not in their best interests. For most decisions, all human beings will take account of what they believe will make them happier, will suit them and, in the main, be good for themselves even when they know there may well be more logical or healthier or more prudent options that they have not chosen. We are all familiar with making what other people might think are unwise choices sometimes or even most of the time but it is simply wrong to think that we ignore our "best interests" when we do that.

One of the most disturbing things about "best interest" decisions made by substitute decision-makers or authorities is that they usually aren't in the person's best interests. A number of writers have made lists about what human beings need in order to flourish and develop as happy and whole persons. The lists usually start with very basic things to sustain life and physical well-being, such as: air for us to breathe; clothes and shelter to keep us warm; food and water to nourish us; access to health services. Then, the lists may describe other things such as friendships and relationships; stimulating activity; spiritual development and so on. What we know is that "best interest" decisions made by people about other people tend to focus, like statutory services, on the basic needs of food, shelter, warmth and safety and the items at the top of the lists tend not to be addressed at all or only in a very superficial way, ignoring the fact that human beings who have substitute decisions made for them have exactly the same needs and desires as any other human being.

Our view is that people making their own decisions will have a much broader view of what their best interests are and will usually take that longer list into account. It might include things which are fun, which taste good, which are relaxing, which support relationships or which please other people so that we get comfort or are better liked or have enjoyment or stimulation or excitement.

However, in law and in academic discussion, "best interests" has come to mean decisions taken by authorities or substitute decision-makers so, in this framework, we will resist the temptation to redefine what "best interests" means as long as we understand that the person's own will and preference will, mostly, reflect the person's best interests even better than substitute decision-making tries to.

In order to incorporate that idea, we have borrowed from some of those lists[3] to create what we have called Universal High Order Preferences which we think most people take into account when they are making decisions. There will be elements of immediate gratification of course, as well as underpinning ideas of identity, curiosity, fun, autonomy, familiarity, sense of belonging, sense of self, fitting in with cultural norms, stimulation, company and society and all the rest.

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[3] Abraham Maslow's Hierarchy; Jonathon Bradshaw's taxonomy, Manfred Max-Neef's Human Needs and Human-scale Development , Joe Griffin and Ivan Tyrrel's Human Givens, John O'Brien's 5 Accomplishments

Universal High Order Preferences			
Need	**Address**	**Include**	**Involve**
Physiological and Subsistence	physical and mental health	food, shelter, activity	eating, drinking dressing, rest, sleep exercise,
Protection and safety	care, adaptability, autonomy	social security, health systems, work	co-operate, plan, take care of, help
Affection and love	respect, sense of humour, generosity, sensuality	friendships, family, relationships, sex, touch	share, take care of, express emotions, give and receive attention
Understanding	critical capacity, curiosity, intuition	books, teachers, policies, educational opportunities	analyse, study, reflect, investigate, think
Participation and belonging	receptiveness, dedication, sense of humour	responsibilities, duties, work, rights	cooperate, dissent, express opinions
Leisure	imagination, peace, spontaneity	Hobbies, games, parties, peace of mind, films	day-dream, remember, relax, have fun
Creation and usefulness	imagination, boldness, inventiveness, curiosity	abilities, skills, work, techniques	invent, build, design, work, compose, interpret
Identity	sense of belonging, self-esteem, consistency	language, religions, work, customs, values, norms	get to know oneself, grow, commit oneself
Freedom and equality	autonomy, passion, self-esteem, open-mindedness	equal rights	dissent, choose, run risks, develop awareness

Throughout the Framework, we argue that supporters of decision-making need to be aware of these High Order preferences and be guided by them in order not to over-simplify the idea of Will and Preference when establishing what the person might want.

The 3 types of Decision-making

People make a range of decisions in their life. Some decisions are simple, and require no or very little support from someone else. Some of these decisions need to be made on a daily basis, others only occasionally. There are also decisions that most people require or want support with. For most people, who have well established social networks and who have learned, from a young age, to make decisions, asking for advice is a normal part of life. It is only natural, then, to argue that people with an intellectual impairment will also require support to make decisions. The amount and type of support that is required will differ from person to person and be dependent on the decision that needs to be made.

Opponents of supported decision-making often argue that some people are simply not in a position to express their will and preference, or that they continuously make 'bad decisions'. This is where a skilled supporter is vital. People First believes strongly that all people communicate, in one way or another. Where communication is extremely limited, it is up to the supporter to interpret the will and preference of the person based on the relationship they have with the decision-maker and everything they know about their life.

Equally, some people argue that supported decision-making will be difficult or impossible if there is conflict between the person's will and preference. In our view, there is often conflict between will and preference when any citizen makes decisions. The two terms – will and preference – are often grouped together as if they were one thing but they are usually not. Preference is a less weighty idea than Will. Will suggests determination after consideration while preference can be a slight or marginal difference of one thing over another, both of which are acceptable. In most of our lives, we have preferences which we do not always act upon but we rarely give up something we "will" to happen. It is fundamental to the role of the decision-making supporter to assist the decision-maker to work out what he or she will ultimately decide after considering as many of the options as possible, many of which might be preferences of the person.

The following table describes the support required for different types of decision-making.

Self-generated and supported Decisions	Supported Decisions	Interpreted Decisions
Supporters provide information and experience that enables the person to decide and act on their own behalf based on their will, preferences and rights and taking account of resource constraints and consequences.	Supporters provide information and experience that enables the person to express their will and preferences and if necessary help the person to refine and adjust these, and assist in taking account of resource constraints and consequences. The supporter assists the person to exercise their legal agency (take action to have will and preferences met)	Supporters provide information and experience and enable the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences. Supporters clarify and refine the person's will, preferences and rights especially if there are likely to be harmful consequences and the person needs more support to appreciate all of these.

Where the person has not been able to articulate will and preference in a refined way, the supporter is charged with working out, based on intimate knowledge of the person, what the person's expression of will, preferences and rights would have been, had they been able to communicate them.

The supporter may also support the exercise of the person's legal capacity, that is help the person put their decision into practice and get things done. |

When supporting someone to make decisions, it is important to remember that every decision will bring with it its own challenges, and will require different levels and types of support. The tables on the following pages serve to illustrate first the different decision-variables and then, the different support variables.

The tables are to be used as guidance about what kind of support is required when, but again, these are suggestions and should be seen as such.

Decision-making Ability

An important aspect to consider when supporting a person with a decision is the person's decision-making ability. General comment number 1, written by the UN Committee on the CRPD argues that mental capacity refers to the decision-making skills of a person. However, in most countries mental capacity has been used to describe the degree of a person's intellectual impairment, and people in Scotland are assessed as either having, or lacking capacity.

The Adults with Incapacity (Scotland) Act 2000 states that:

For the purposes of this Act, and unless the context otherwise requires—
- "adult" means a person who has attained the age of 16 years;
- "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,

The UN, however, rejects the use of capacity assessments of any kind and argues that: "Mental capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity." This means that not only is the person's ability to think and act affected by where the person lives and how the person is treated but the people who assess capacity also do that differently depending on where they live and the rules they live under. There is no universal agreement about how to assess mental capacity.

This framework is based on the concept of mental capacity as used by the UN Committee, but we call it decision-making ability, to avoid confusion for decision-makers and their supporters.

Each individual will have had different experiences of choice and control over their life and each decision will affect the decision-maker slightly differently. It is important that these factors are looked at for every decision that needs to be made, and for the support to be adapted accordingly.

In our view, **Decision-making ability** is made up of the following components:

Information – the amount and quality that is available to the decision-maker and how understandable it is.

Number of options and how familiar they are to the decision-maker and how readily they can be compared to each other in the process of weighing them up.

Awareness and understanding of consequences of deciding on any of the options, including the attitude of other significant people in the decision-maker's life.

Personal security – this is made up of confidence, level of self-esteem, previous experience of making decisions, awareness of rights, willingness to risk disapproval versus drive to seek approval.

Linking and connecting ideas – since most decisions have different elements and components such as "if this, then that..."

Communication – both in ability to hear and understand information and to articulate one's own ideas, preferences and reservations and includes the ability to seek clarification of information

Comfort with new experiences and with risk – where the decision-maker has had very limited experiences and has a fixed pattern, it will be much more likely that there will be discomfort in deciding to try something new or unfamiliar. Similarly, if the person has been brought up to be afraid of risk, that will affect decision-making also.

The following two tables help to illustrate the different types of decisions that people are required to make in their lives, as well as the kind of support that may be best suited to the different situations.

It is vital to bear in mind that this will be different for each person. What is a simple decision for one person, may appear complex to someone who has had very little opportunity to develop their skill and confidence in decision-making. Similarly, support networks will vary for each person. Good practice means assessing, alongside the decision-maker, what kind of support (if any) is required for different decisions.

Decision Variables

Kinds of decisions	Routine	Occasional	Rare	Exceptional
Simple	Meals, Entertainment, Clothing	House decoration, Buying gifts	Going to the circus, Hairstyle change	Growing a beard
Important	Exercise, diet, Personal Relationships	Selection of support staff, Birth control	Medical treatment, Pets	Bereavement
Complex	Personal Relationships	Holiday	House move	Life-changing surgery

As stated throughout this framework, each decision will be different for every person. For a person who has had a lot of life experience, and who has experience in expressing their preference, choosing house decorations may be a very simple decision. For another person, who has had little opportunity to make decisions or who feels dependent on the approval of others, this can be a complex decision. Every decision that needs to be made needs to be assessed in light of the person's life experience as well as their decision-making ability, as discussed previously.

Support variables

Kinds of supports	Routine	Occasional	Rare	exceptional
Social care support	Simple decisions only	Simple decisions only	Simple decisions only	Simple decisions only
Family members or friends (can also be formal appointed decision-supporters)	Simple, Important and Complex decisions unless there is significant conflict of interest	Simple, Important and Complex decisions unless there is significant conflict of interest	Simple, Important and Complex decisions unless there is significant conflict of interest	Simple, Important and Complex decisions unless there is significant conflict of interest
Independent advocates (formal appointed decision-supporters)	Not usually involved at this stage	Important, rare or complex decisions	Important, rare or complex decisions	Important, rare or complex decisions

For everyday decisions which are relatively routine, we envisage the person receiving support from a range of available people. For people with strong and close family connections, this is most likely to be a close family member. For people with less strong or more distant family connections, support workers and service workers will probably be in the front line for offering support. Support workers who often have the most contact with people, offering day-to-day support are, however, required to work from a duty of care perspective. This usually leads to risk-averse practice and it can therefore be very difficult for support workers to support autonomous, and potentially risky decision-making. It is important to take note of this when considering the kind of decision the decision-maker needs support with.

For more important decisions, support workers and service workers will be less likely to be involved but family supporters, where these exist, might well be. Even at this

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level, there may be conflicts of interest for family members and the training offered should include training in identification of conflicts of interest and strategies to manage these and minimise the conflicts.

For very complex and rare decisions such as moving from the family home, starting or leaving a job, consideration of life-changing medical treatment, deciding to move in with a new person, for example, it would be better to involve a registered decision-supporter and, for family members who are themselves registered, to involve another registered supporter who is not a family member. It might well be possible to do this work in tandem providing the decision-maker is not burdened by conflicting guidance or advice.

Advice is always a component of decision-making support and any attempt to pretend that it is not in the picture is unhelpful and potentially harmful to the person making the decision. As members of society, we have learned to ask others for advice and would often be disappointed if this wasn't offered. We have also all had experiences of advice being offered too soon, or being offered when it is not welcome – perhaps because the other person is trying to persuade us that their advice is the only way to proceed. Genuine, measured advice is an integral part of support for decision-making for people with intellectual impairments, as it is for all members of society. The case examples in the Appendix help to illustrate how advice may be offered.

Again, every decision or choice will be perceived differently for each individual and is also likely to be influenced by how the decision-maker is feeling at the time. Supporters should not make assumptions about how difficult a decision is or how much support a person may require, but should be guided by the decision-maker for each individual decision.

The different levels of support:

The variables diagram following this section gives visual representation to some of the variables that might affect how much support should be provided to the decision-maker. This section will explain in more detail what the differences between the different levels of support may be but it is important to remember that this too will vary from person to person.

In general, **low level support** involves the supporter providing information, perhaps discussing the decision and possible outcomes or consequences with the decision-maker and reviewing the decision at a later point (if this feels necessary).

Medium level support would include all of these elements but more time will be allocated for the supporter to discuss the decision and the different outcomes and consequences with the decision-maker. The decision-maker may need more time to make the decision or may feel less confident in making the decision.

High level support also incorporates the elements mentioned above but the support is expected to take place over a longer period of time, with more input from the supporter regarding exploration of options, and it is possible that the information relevant to the decision needs to be shared on a few occasions – when the decision-maker is ready to receive it – and the decision made reviewed on a few occasions to ensure the decision-maker is committed to the decision and genuinely wants to follow through with it.

Interpreted decisions

An interpreted decision is where the person is either unable to verbally communicate will and preference or has great difficulty in doing so. This could be because of limited communication or severe intellectual impairment or for any other reason. In this instance, the decision-making supporter has to interpret what the person's will and preference are or are most likely to be. The supporter does this through close relationship with the person, intimate knowledge of the person and his or her likes and dislikes and skilful reading of the facial expression, body language and sound cues given by the person.

Interpreted decisions can fall into any of the 3 categories of low, medium or high level support. For example, where a person has a very well-known preference for what to eat for breakfast, it is unlikely that it will require a great deal of time to ask the question, explore options and interpret the person's will and preference. It is also wrong, however, to automatically assume what the person would like without any exploration whatsoever simply based on habitual selection, so the intention would be: from time to time, to test out whether the person might wish to change the preference. The same would be true of less simple or routine decisions. The level of support should be tailored towards what the person will require in order to be assured that the decision was made by the person him or herself.

Some people have suggested that interpreted decisions are not any different from substitute decisions and that this level of intensive support is the same as making the decision for someone. We would fundamentally disagree since substitute decisions are primarily based on what the substitute decision-maker believes is in the person's best interests and supported decision-making is based on the person's will and preference as well as rights.

> General comment No. 1 (2014) of the UN Committee says:
> Article 12: Equal recognition before the law
> 29(b) All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests;

The role of a Guardian or substitute decision-maker is to make the decision for the person usually based on best interest considerations. The role of a decision supporter in this case is to interpret what the person's will and preferences would

have been if they could express them and interpret the decision they would have made.
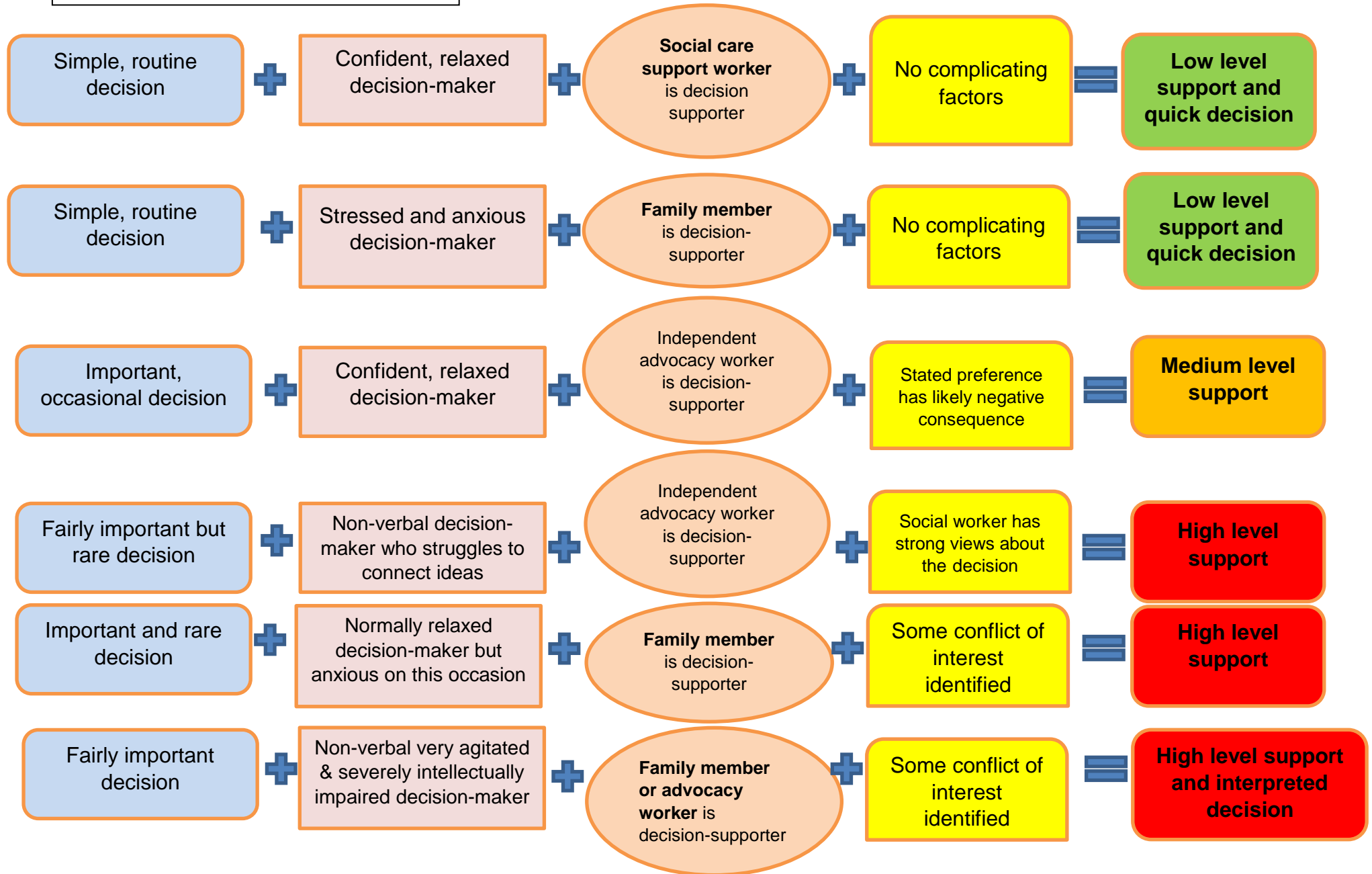
When interpreting a decision made by a decision-maker, it is important to follow all the 'steps' of the decision-making process, and information is offered to the same extent that it would be offered to decision-makers in other scenarios. An interpreted decision of the will and preference of the decision-maker can only be made once the process of offering support, as described above, has happened.

When offering different levels of support, it is important to be guided by the decision-maker on how much, and what kind of support they require. It is always necessary to bear in mind, however, that the aim of supported decision-making is for people to learn the skill of decision-making and develop confidence in their ability to make decisions. High level support should therefore only be offered when it is really needed, not on a routine basis, as it may be detrimental to the development of skills and confidence. It may also exhaust the tolerance of the person and it is important not to make the decision-support process into something unpleasant for the decision-maker.

The variables outcome diagram overleaf helps to illustrate how the interaction of different variables may affect the level of support that is required. As mentioned above, the diagram serves as an illustration but for every decision-maker the variables will be different and require different input.

When using the diagrams in this document it is important to consider them alongside each other, and to remember that they are illustrative and not prescriptive tools.

Diagram of variables and outcomes

Simple, routine decision	**+** Confident, relaxed decision-maker	**+** **Social care support worker** is decision supporter	**+** No complicating factors	**=** **Low level support and quick decision**
Simple, routine decision	**+** Stressed and anxious decision-maker	**+** **Family member** is decision-supporter	**+** No complicating factors	**=** **Low level support and quick decision**
Important, occasional decision	**+** Confident, relaxed decision-maker	**+** Independent advocacy worker is decision-supporter	**+** Stated preference has likely negative consequence	**=** **Medium level support**
Fairly important but rare decision	**+** Non-verbal decision-maker who struggles to connect ideas	**+** Independent advocacy worker is decision-supporter	**+** Social worker has strong views about the decision	**=** **High level support**
Important and rare decision	**+** Normally relaxed decision-maker but anxious on this occasion	**+** **Family member** is decision-supporter	**+** Some conflict of interest identified	**=** **High level support**
Fairly important decision	**+** Non-verbal very agitated & severely intellectually impaired decision-maker	**+** **Family member or advocacy worker** is decision-supporter	**+** Some conflict of interest identified	**=** **High level support and interpreted decision**

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The following sections deal with the practicalities of becoming a supporter, and consider safeguards and principles of support for decision-making.

The Process of *becoming* a registered decision-making supporter

1. The person who requires support asks the other person to become their decision supporter. For people who are non-verbal, the invitation can be inferred or interpreted by the decision-maker's level of acceptance or enthusiasm for being in the nominated supporter's presence and the level of tolerance for the duration of their company.

2. The nominated person agrees to take on the responsibility either informally or more formally.

3. For some people, this simple contract will be enough but for many people, a level of formal recognition will have some benefits such as official recognition of the relationship and, on the part of the supported person, some scrutiny of the relationship and how well it works and meets the principles.

4. The nominated person approaches the Supported Decision-making Registrar wherever that is located. Possible locations might be: Mental Welfare Commission Scotland; a Learning Disability Commissioner's office if that is set up; the Office of the Public Guardian if that were to have additional powers and responsibilities; the Scottish Social Services Council alongside their existing registration functions; Disclosure Scotland alongside their existing PVG Scheme membership and barred lists.

5. Some basic level of scrutiny will happen. This should include an assessment of the proposed decision-supporter's suitability including any offending history, any inclusion in barred lists (PVG Scheme) and the character of the applicant. Ideally, there should be an existing relationship which the decision-maker has been happy with but in some cases, this will be the beginning of a new relationship. The Registrar will, having satisfied him or herself of the applicant's suitability and upon successful completion of the training, issue a certificate identifying the applicant as the registered supporter for X's decision-making where X is the person requiring support.

6. In some instances, there will be more than one person registered as decision-supporter for an individual or an applicant may be registered to support more than one decision-maker although that might increase the potential for conflict of interest. .

It is important to note at this point that informal advice and support for decision-making is part of daily life. We do not advocate that everyone who comes into contact with the person, i.e. a hairdresser who offers advice and support, should be registered. Registration is a way for supporters who spend a significant amount of time with the person, and who know them well, to be recognised in their role. The registration process will lend credibility and recognition to any supporter where they will be involved in most decisions of a person's life.

The process of *staying* as X's registered decision-making supporter

1. X can, at any time, approach the Registrar and say that the registered person is no longer their preferred supporter. That will terminate the registration for X. Another person can be nominated and apply to become X's new supporter.
2. The nominated support person can, at any time, decide not to continue with the role. He or she should inform not only the person who had been supported but the Registrar who will record the supporter's removal from the register for that person and, if necessary alert appropriate bodies that an alternative supporter is required.
3. There will be regular scrutiny by the registration body or similar body and feedback will be given on the role performance and additional training and/or support may be offered in the role.
4. Where the supporter is in a formal role (such as independent advocate and not a family member or friend), the employing agency will have to continue to allocate time to the role. Where the supporter leaves the job or changes role, the Registrar will need to be informed and records amended as in 2 above.

The process of Support for Decision-making (the "steps")

Before examining the steps of decision-making it is important to remember that as with everything in this framework, an individualised approach will be required. It is possible that some steps will have to be returned to: for example, if a decision has been refined it is possible that the need for more or less support is then identified before moving on. It's important that all steps are part of the process but the time spent on each may vary. Decision-makers may also find some steps more difficult than others so the time spent on the different steps will vary. The support should follow the entire process, however, and explore with the decision-maker any aspects of the process they find challenging. Different decisions will also affect the steps as a 'simple' decision may need less attention at each step than a 'complex' decision.

1. The support person is identified either:
    a) Directly by the person him or herself
    b) By virtue of the established relationship which has been accepted by the decision-maker over time and ratified by formal registration
2. The support person accepts the role and has the option of becoming registered
3. The support person and the decision-maker build a relationship together if that does not already exist. Time must be set aside to establish and develop the relationship
4. The decision to be made should be identified and named so that both parties (supporter and decision-maker) are clear and agreed about the subject under discussion. There may be more than one decision required at any time and each decision may well have a number of connected themes.
5. Establish the level of support required by the person to make the decision. It is not at all uncommon for people to initially minimise the level of support
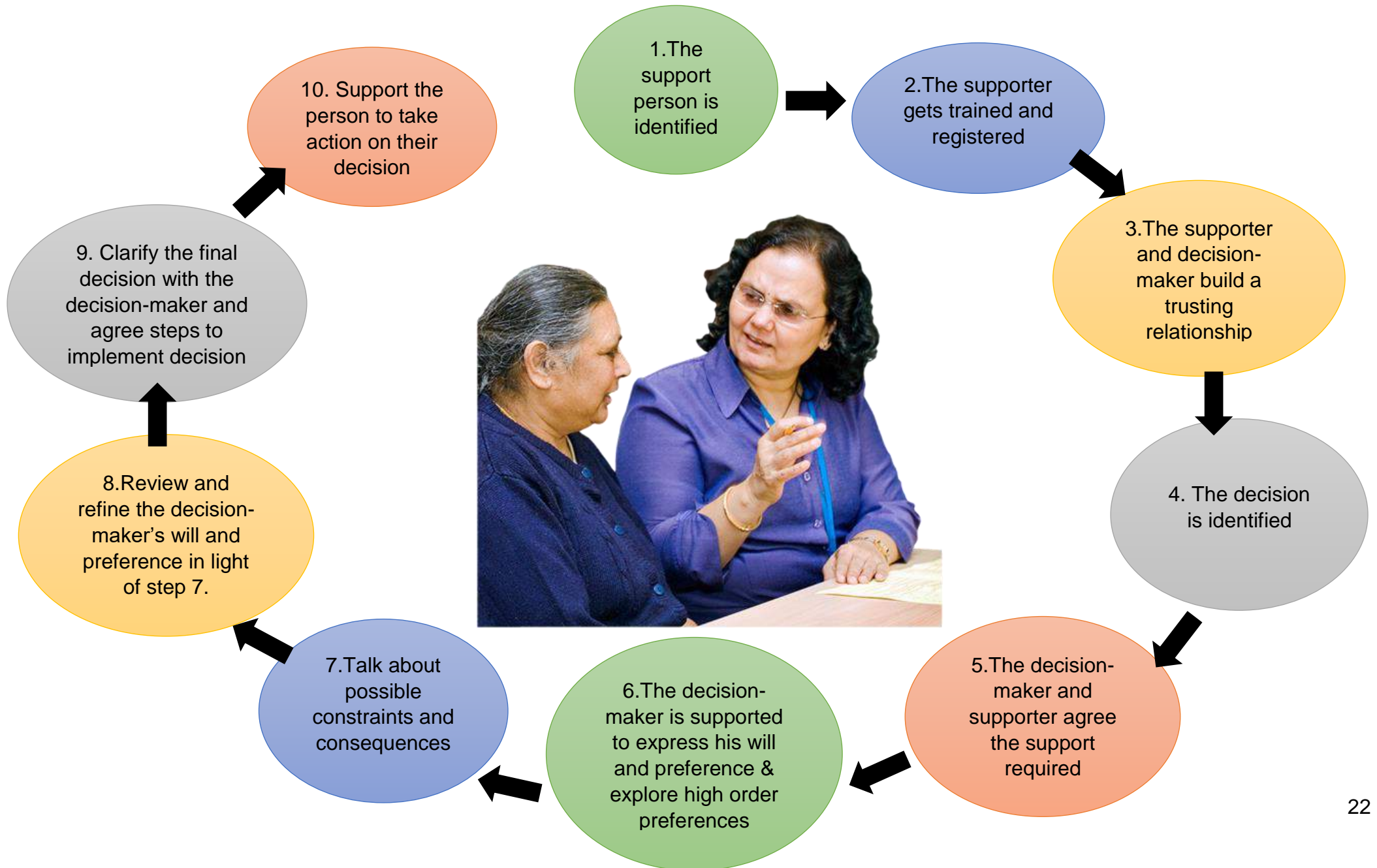
needed and to maximise their ability to operate without support. The relationship with the supporter should allow the person to be comfortable enough to honestly and authentically describe the need for support. Remember, the support needed will likely vary from decision to decision.

6. Support the decision-maker to express his or her will and preferences around the decision. Remember that the first expressed preference may not be what the person desires most. They may not be aware of all the possibilities, constraints and consequences. Spend time understanding the decision that needs to be made and exploring the high order preferences (the things that all human beings need and value in their lives) with the person being supported.

7. Take time to explain to the person as many of the options as is feasible, covering any constraints and explaining likely consequences of any decision.

8. Together with the person, review and refine will and preferences in the light of identified additional options and any constraints or likely consequences.

9. Clarify with the person what their final decision is and agree what will need to be done to attempt to implement the decision.

10. Support the person to exercise their legal capacity – making efforts to have the person's decision take effect.

As a supporter it is important to remember, and support the decision-maker to understand, that not all decisions we make in life will take effect. This can be due to external factors such as circumstances, or may be denied by other people who hold more power over resources or goods and facilities. Making a decision will not automatically lead to the desired outcome but people with an intellectual impairment have as much right as everyone else to attempt to turn those decisions into actions and reality. If it becomes clear that a desired outcome cannot be achieved, the decision-maker can then be supported to think of an alternative. It is important that the person is offered the opportunity to make the decision that is right for them and a good supporter will explain possible constraints where these are foreseeable, but will also encourage the decision-maker to continue the process of making the right decision for them, even if the initial outcome was not achievable.

We have included item 10 above – support for the person to exercise their legal capacity – this is clearly connected to the previous items and is part of the process but it is a little different. The exercise of legal capacity – acting on the decision – only happens when the decision has been made (with support) and is something much more straightforward and could, in fact, be done by any number of people even if they are not decision-making supporters. For example, if the crucial decision is to move out of the parental home, the exercise of legal capacity would include: telling one's parents; applying for one's own accommodation; letting others know of a change of address, for example. Other decisions might follow such as which offered accommodation to accept and whether or not to share with other people and how to choose them.

The 'Steps' of Supported decision-making

1. The support person is identified

2. The supporter gets trained and registered

3. The supporter and decision-maker build a trusting relationship

4. The decision is identified

5. The decision-maker and supporter agree the support required

6. The decision-maker is supported to express his will and preference & explore high order preferences

7. Talk about possible constraints and consequences

8. Review and refine the decision-maker's will and preference in light of step 7.

9. Clarify the final decision with the decision-maker and agree steps to implement decision

10. Support the person to take action on their decision

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Principles of supported decision-making

Before becoming a supporter for decision-making every person has the absolute obligation to consider the huge responsibility that comes with being in this position. Throughout this document we have used words such as 'feasible', 'realistic decision' 'as far as possible' etc. These words contain some element of judgement and discretion and are indicators of the power that supporters have to influence the process. It goes without saying that supporters should strive, at all times, to do the right thing for the decision-maker. Part of that responsibility is working reflectively and paying close attention to one's owns values. Supporters for decision-making will have to continuously work to do 'the right thing', disregarding their own needs and preferences in favour of those expressed by the decision-maker.

The following principles for supporters must be adhered to at all times in order to ensure that the process of support is measured, fair, and free from undue influence.

1. Decision making steps should be driven, as far as possible, by the decision maker her or himself.

2. It is important that the decision maker feels comfortable enough to express herself through each step. Encourage her to say what she thinks or feels, even if you, as the supporter, don't agree with it.

3. Sometimes you can make substitute decisions without realising it – always check to make sure the decision maker is in charge.

4. Encourage the decision maker to keep other people in his life involved- it will help the decision making steps progress and ensure you don't feel overwhelmed with responsibility.

5. You may need to revisit a step more than once.

6. You can start small – try a few easy decisions before getting on to the big decisions. This can be an indication of progress towards becoming accepted and trusted to receive the decision-maker's views and preferences.

7. Be flexible in your approach. Different steps of the decision-making process may appeal more to the decision maker than to you. For example, the person you support may want to rush through the exploration of options, or they may get 'stuck' at this phase. It is a good idea to try out each step when you are first getting started.

8. Some decisions will take time. Let the decision maker know that they don't have to rush and that you can support them in their own time.

9. It is ok for the decision maker to make a mistake or to change their mind – everyone does at times.

10. Sometimes the decision maker might want you to make the decision because it is hard for them. Take time to work through their concerns and encourage them to keep going.

11. It is crucial to remember at all times that supported decision making is about assisting the decision maker to make the decision that they think is best for them, which may not be the same as the option you think is best for them.

12. All people, without exception and regardless of the degree of intellectual impairment have the right to make their own decisions about their own lives with the support that they need.

13. No-one should ever have to pay for support to make their own decisions.

Safeguards:

The UN Committee, in General Comment no.1 stresses that safeguards must be set up for all processes relating to support in exercising legal capacity. Safeguards for such support must be premised on respect for the rights, will and preferences of persons with disabilities. The most effective safeguard is good support, as outlined in this framework. Good support will enable a person to think through their options as well as their consequences. Good support will challenge the individual but never take away their right to make decisions that reflect their will and preference. Further safeguards are explored below.

a. Training for supported decision-making

Training for supporters acts a safeguard as it ensures that supporters fully understand the principles and process of supported decision-making.

Training for supported decision-making will be delivered by People First (Scotland), incorporating user-led experience as well as relevant knowledge transfer and theory. The training could be marketed by the Registrar.

Training for supported decision-making will be based on case-studies and be interactive in its approach. Training will be delivered in small groups but a web-based system could also be available to those who live in more remote locations. If funding is available, we could take the training out like a roadshow.

b. Registration of Supporters

We envisage a system where supporters are encouraged to register with the Supported decision-making Registrar, wherever that may be situated. Family members will have the option of registering as supporters once they have completed the support for decision-making training. No one may be registered unless they have successfully completed the training.

The benefit of registration is that, especially for family members in that role, there will be recognition by public authorities that there is a duty to include the registered supporter alongside the person in any decisions being made. There is also the

required Safeguard (UNCRPD) of a registration body where complaints about a decision-supporter's actions or behaviour might be brought.

c. Managing Conflict of Interest

Conflict of interest occurs when the person supporting the decision-maker has competing interests or loyalties connected to a decision which could be made by the decision-maker. This could be because the supporter might benefit either financially from a specific situation, or they could fear the impact on their reputation if the person they support makes a decision with a negative outcome. However, it could also be as simple as one outcome being more convenient than another for the supporter or even to someone else that the supporter might be in a relationship with.

When supporting someone to make decisions it is essential that the supporter pays close attention to any potential conflict of interest that may arise. If a supporter identifies their preference for a specific outcome, good practice would suggest either asking someone else to support that decision, or working reflectively and actively ensuring that the conflict of interest doesn't affect the support that is offered. This can be very difficult and this framework recommends supporting the decision-maker to identify a supporter who has no conflict of interest in relation to the decision. A good supporter will be aware of any conflict of interest and work towards ensuring they do not exert any undue influence, or if they feel unable to do this, support the decision-maker to nominate a different supporter.

d. Avoiding Undue influence

Undue influence is when a person is made to act in a way that is different to their free will, by someone who is in a position to do so, such as any of the people who might become decision-making supporters. The methods might be aggression or threat but are far more likely to be subtle such as manipulation or taking advantage of the relationship of trust by withholding information or giving false information and unsound advice. Undue influence is likely to occur where conflict of interest has not been recognised or is poorly managed.

e. Managing situations of risk and harm

Many people worry about how supported decision-making would work where there were decisions which could lead to risk or harm to the decision-maker or someone else. Our view is that there is probably more safety with supported decision-making than under a substitute decision-making regime. Under substitute decision-making, the person is simply told "I will make that decision for you – you are not allowed to make that decision". There is nothing in substitute decision-making which prevents the person, nevertheless, doing the risky or dangerous thing. Other measures would have to be applied such as detaining or confining the person. Of course, with finances, the person who has had their legal capacity removed is simply unable to spend money in a risky or dangerous way but we all know that there can be other ways of getting hold of money or resources if the person is determined to do

something. The fact is that the guardian, unless it is a close family member, most often is not physically alongside the person to see what they are doing. With supported decision-making, the decision-making supporter is likely to have more frequent contact with the person, is in a position to discuss and debate with the person and has a responsibility to guide, inform and advise the person, most especially if the person seems about to decide something which could cause harm or bring unacceptable risk. The decision-making supporter should never, in this model, agree with a decision which would lead to unacceptable risk and has an obligation to stick with the process to identify alternative options and assist the person to manage risk and avoid harm.

This process, in fact, closely mirrors the process most commonly experienced with Adult Support and Protection measures at present and we believe that a partnership between supporters of decision-making and the existing adult protection processes provides a good level of protection against risk and avoidance of harm. The legal powers under the Adult Support and Protection (Scotland) Act 2007 are very rarely used. The numbers of Assessment Orders, Banning Orders and Removal Orders actually implemented is very small indeed and, instead, Adult Protection Officers and the Committees much more commonly engage in discussion and exploration of options in a way which is consistent with the decision support process we have described in this framework. Under a Guardianship regime, there is very often a legal and policy barrier to the Adult Support and Protection process properly investigating the risk of harm to an adult and those barriers would cease to exist under a supported decision-making regime.

Resources

In order for a system of supported decision-making to be established and maintained in Scotland, compliant with the UN Convention on the Rights of Persons with Disability, some resources will, of course, be needed.

We believe, however, that the costs of the current system of substitute decision-making are more than they need to be and that, over time certainly, there will be financial savings to the state of a supported decision-making system which replaces Guardianship. There will be considerable savings in costs to the time of the courts and judiciary and to the Legal Aid system. There will be a reduced cost to the time of local authority social workers and Mental Health Officers and a significant saving to the time of Approved medical practitioners and other doctors.

In exchange, we think there will need to be some spending on:

- capacity building/training for decision-making supporters
- a system set up for registration/monitoring
- Additional funding for advocacy to provide advocacy workers who can be trained and specialise in supported decision-making

Appendix A:

Case example **Self-generated and supported decision**

In this case, we will consider a Gail, a young woman who is verbal, intellectually impaired to a relatively moderate degree, who reads reasonably well and travels by herself even to some unfamiliar places. She converses well and has a wide vocabulary.

In this instance, she has a decision-supporter who is her mother, Anna, who has attended supporter training and has registered as Gail's decision-making supporter.

Gail has declared that she wants to go to college and study child care with a view to finding paid employment in a nursery or child-care centre.

Anna initially discusses with Gail where this ambition comes from and how strongly she feels that this is the career path she wants. She presents to Gail a number of alternative options to consider alongside child care including hairdressing, retail sales work, care for older people, reception work in the hospitality industry, all of which involve a college course of some kind. Gail does consider the alternatives but sticks with her initial preference of studying child care. Anna then spends time making sure that Gail understands that she may not be successful in her application and even if she is, she may not succeed in passing the course and even if she does, she may not be able to find employment in the industry. Gail, at first, is angry and accuses Anna of not supporting her. Anna remains calm and expresses her commitment to explore ways to increase Gail's chances but stays firm with the idea that Gail must think about what she will do if this plan doesn't work for her. Gail eventually discusses how disappointed she would be and how committed she is to working hard to try to succeed.

At this point Anna gathers information about the college courses available and downloads application forms for college courses at different levels. Gail expresses a preference for the National Certificate in early education and child care. Anna explains that applying for the Entry to Early Education and Childcare course would be more likely but the better plan would be to try for the Skills for work in Childcare course which, if she got that, would go towards entry to the Entry to Early Education course which could then go towards the National Certificate course. There was some complicated information about the SQA level of study for each course and Anna's recommendation would be at level 4 rather than the others at level 5 or 6. Gail finally agreed that she would decide to apply to the Skills for work course but made it clear that if she managed that and got the qualification, she intended to do the National certificate course next. Gail asked her social care support worker to help her fill in the application form.

Case Example **Supported decision**

In this example, John is a 62 year old man who lives on his own and receives a 12 hour a week package of social care support. John's speech is quite difficult to understand and he becomes frustrated if people do not understand what he is saying. He is quite significantly impaired. He does not read at all and enjoys listening to music and watching films on satellite television and DVD. He is also mobility impaired and is very unsteady on his feet, especially if he is tired and he risks falling over. He uses a walker to assist his stability and he does travel quite independently on public transport but only to places he has been to before. Any new destination requires a support worker to accompany him.

John's decision supporter is Ellen, an advocacy worker from a nearby independent advocacy project who is registered as John's decision-making supporter.

John has become unhappy with his social care keyworker. He feels the worker is impatient with him and does not listen enough to what John says. He asks Ellen what he can do about the problem. Ellen firstly explores the nature of the problem but John is not able to say much more than he is not happy with the worker. Ellen asks how long John has felt that way and what he has tried to do to address the problem. John does say he has told the worker and spoken to the team leader but nothing has changed. At this point he says "it doesn't matter" and that he wants to forget it. Ellen, however, disagrees and says to John that it does matter and advises him to stick with it and try to get it fixed. John agrees to take the advice.

Ellen presents what she sees as the main options:
1. Meet with the support worker with Ellen helping John to say how he feels
2. Make a formal complaint with Ellen's help
3. Ask for a formal meeting with the social worker and service manager with Ellen's help to get a different support worker allocated
4. Ask for a meeting with the social worker to get a change in support provider
5. Ask for a Direct Payment and appoint his own support staff

Ellen provides information on all of the options and explains the upside and downside of each and what could happen with each option both positively and negatively. John decides that he would like to give the worker another opportunity to change so decides on option 1 and then, if that doesn't work, to go to option 3.

Case example – Interpreted decision-making

For our example of interpreted decision-making, we are going to use a case presented by Adrian Ward to the Fourth World Congress on Adult Guardianship, on 14 September 2016.

Adrian said:

> "When we have to make a difficult decision, we often have to balance conflicting preferences. Even more importantly, those three elements [the rights, the will and the preferences] may be in conflict with each other. Here is a simple example from my own experience. A young man had severe learning disabilities, sometimes with challenging behaviour. He could communicate only through the interpretation of his behaviour by skilled carers who knew him well. His behaviour deteriorated. He aggressively resisted anyone or anything going near his mouth. His clear will was to stop any interference with his mouth. His preference was that the toothache which he had developed should end. His right was to receive appropriate healthcare. Support meant ensuring that he received treatment, using legal measures to assure the dentist that he could properly deliver it."

However, if we apply the framework of supported decision-making, and include the idea of universal high order preferences, we believe that there is no conflict. If the decision-making supporter were to ask, "Do I think that the young man wants people to stay away from his mouth because he wants to keep the toothache?" then the answer would clearly be "no". The young man, simply reacting to the pain, wanted people to stay away from his mouth in case they made the pain worse. He may have been partly right. A care supporter might inadvertently have caused him more pain by offering food, assisting with tooth brushing, wiping his face, for example. In any case, his will, we believe, is relatively easy to interpret as "ending the pain and avoiding more pain" and his preference we agree, was that the toothache should end and his right was to good health care and dental treatment.

In this case, the correct interpretation of will and preference is that the young man has a wish for dental treatment to end the toothache but delivered in a way that is, as far as possible, not painful, not distressing and effective.

If the young man was able to understand the question:
"Would you like me to give you something that will help you sleep for a while and when you wake up, the toothache will be gone? It may be a little tender for a couple of days but the awful pain will go away." Do we think that his response, if he could give one, would be 'yes' or 'no'?

Appendix B

Some of the reading we have found useful:

Filling the Bournewood gap – Adrian Ward
Article from the Law Society of Scotland Journal 15 December 2014

Best interests decision-making under the Mental Capacity Act - The Essex Autonomy Project

The Essex Autonomy Project three jurisdictions report Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK 6 June 2016

General comment No. 1 (2014) Article 12: Equal recognition before the law Committee on the Rights of Persons with Disabilities Eleventh session 31 March – 11 April 2014

Person-Centred Active Support – Increasing Choice, Promoting Independence and Reducing Challenging Behaviour - Julie Beadle-Brown*, Aislinn Hutchinson and Beckie Whelton, Journal of Applied Research in Intellectual Disabilities 2012, 25, 291–307

Supported Decision Making: A handbook for supporters – Family and Community Services – New South Wales Government, Australia

Support for Decision Making A Practice Framework; Professor Christine Bigby & Professor Jacinta Douglas, La Trobe University New South Wales January 2016

Legal protection of adults – an international comparison – Adrian Ward, Article from the Law Society of Scotland Journal 17 October 2016

Early Deliberation on Graded Guardianship Sandra McDonald Public Guardian Office of the Public Guardian November 2011

Consultation on the Scottish Law Commission Report on Adults with Incapacity – Mental Welfare Commission Scotland

Early Deliberation on Graded Guardianship – Law Society of Scotland, September 2012

Legislating personhood: realising the right to support in exercising legal capacity - Eilionoir Flynn and Anna Arstein-Kerslake, International Journal of Law in Context, 10,1 pp. 81–104 (2014) © Cambridge University Press 2014

A New Paradigm for Protecting Autonomy and the Right to Legal Capacity - Prepared for the Law Commission of Ontario By Michael Bach and Lana Kerzner October 2010

General comment on Article 12: Equal recognition before the law - Committee on the Rights of Persons with Disabilities Eleventh session 30 March–11 April 2014

Comments submitted in response to the Draft General Comment (DGC) on Article 12 – Dr Lucy Series Cardiff Law School Cardiff University