

Supporting Decision Making

Background

You will hear 'supported decision making' referred to in various ways, as supported decision making, or as support for decision making, or as supporting decision making, or as support for autonomous decision making, or even as support for the exercise of legal capacity, but whichever way it is referred to it all amounts to the same thing in practice - offering support to an individual to assist them to make their own decisions. Everyone has a right to make their own decisions, as far as they are able.

The requirement to support a person to exercise that right comes from the United Nations Convention on the Rights of Persons with Disabilities. For ease this is abbreviated to the UNCRPD. The UK has ratified the UNCRPD; in non-legal terms this means we have agreed to respect the requirements of the Convention. The Convention sets out a framework for the respect, as a nation, we are expected to show a person with disability. Disability includes a person with an intellectual disability, cognitive or volitional impairment.

In short, if you are dealing, in any way, with a person who has any level of intellectual impairment you must respect the requirements of the UNCRPD. This Fact Sheet deals specifically with Supported Decision Making (SDM), there is a separate Fact Sheet on the obligation to respect Rights, Will and Preferences, as well as one on the principles of the Adults with Incapacity (Scotland) Act 2000, which you are always required to respect.

SDM Benefits

The benefits of SDM, when carried out appropriately, have been shown to include increased confidence for the individual being supported, increased autonomy and a resulting participation in a greater range of activities. There is less need for guardianship, indeed a few guardianships have been recalled as a result of improved SDM. The person offering support often reports a satisfaction in seeing the increased autonomy of the person they support.

Decision Making Ability

Assessment of decision-making ability should not be conflated with assessment of capacity, they are distinct, someone may be, by definition, incapable but may nonetheless be able to make a decision on a given matter, albeit with support. Like capacity though, decision making ability is not all or nothing, it is not a case that one passes a point where one is not able, thereafter, to make any decision. Neither is decision making ability linear, it is not a case of a person being able to make a low-level decision but not able to make a higher-level decision. Decision making ability must be assessed for each decision.

Factors Affecting Decision Making

There are a myriad of things which impact on anyone's ability to make a decision. Here we look at some of the more common ones.

Experience and Confidence

If you have had a positive experience with a particular decision this may give you confidence to make a decision of a similar nature and, conversely, if you've had a bad experience you may lack the confidence, or be hesitant, to make a similar decision at a later date.

Understanding

If you don't have all the information, don't recognise the importance of the situation, don't appreciate the risks, benefits or rewards you won't be able to make, or make a properly considered, decision.

Emotion

If you are in a difficult emotional time you may find it hard to make a decision, or make a well-judged decision. If you are stressed or anxious about a matter your decision-making ability will be affected.

Other people

You may feel inclined to make a decision to please, or maybe annoy, someone else. You may feel pressured by someone. Someone whose views you value may put you off a decision you may otherwise have made, or may spur you on.

Time of Day

We may naturally be better at making decisions at a particular time of day; or we may be affected by external factors. For example, a parent under pressure in the morning to get the kids up, dressed, lunches sorted, off to school may be better waiting until later in the day to consider a key matter.

Pain

We will be less equipped to make good judgments if we are in pain. Medical treatments may impact on our ability.

Money

A lack, or even an excess, of money may influence a decision.

Lack of Support

You may feel you wish to chat the decision through with someone but have no-one, or no-one suitable, available.

Environment

A calm, quiet, environment may assist decision making – many people say they make their best decisions in the bath, or in bed. For others, background noise helps them think.

Tiredness

Your decision-making ability will be affected by tiredness e.g. from lack of sleep, or at the end of a hard weeks work, or after a long drive.

Lack of Concentration

You will find decision making harder if your thought process is being interrupted or if you are being distracted, or lack concentration for other reasons.

This list is by no means exhaustive, it would be easy to go on; but there is sufficient to demonstrate just how many factors influence decision making.

Things get even more complex when one 'overlays' some of the issues that may be specific to a person's medical condition and impact on their ability to make a decision, so things like

- Attention deficit
- Panic disorders
- Irritability
- Rigid thinking
- Paranoia
- Controlling impulses
- Hearing loss
- Suspiciousness
- Apathy / drive/ motivation

Supporting Decision Making

Eliminate all of the obstacles

To support someone in their decision making successfully requires you first to get to an optimal position on all of the factors that impact on the person's ability to make a decision, some of which are outlined above. So, for example, make sure they are pain free, not overly tired, in a familiar environment etc.

Be clear about the decision to be made

When you are asked multiple questions in the same sentence it gets confusing, and even more so if the answer to one of the questions is yes and the other is no, the person awaiting your response is then also confused as to which response you are giving to which question. In a similar way, it is hard to get to a definitive decision on something if one is not clear, from the outset, what the matter is on which a decision is required. Thus, make sure you make it clear to the person you are supporting, in easy to understand terms, what the matter is you are asking them to consider and decide on.

Take time

In making a decision, many of us need time to consider the issue, then further time to ruminate on our decision, before confirming it is the way we wish to proceed, or not. And likewise, we can feel constrained in our ability to make a decision if we feel under pressure.

Ensure you take sufficient time when supporting a person with their decision making. The time necessary will vary person by person and depending on the issue – be guided by the individual.

Your approach

Check first if the decision maker wishes you to support them in the process. The decision maker has the right to decide if they want decision making support in any specific instance.

Check too if they wish you to be that supporter. The decision maker has a right to choose whom they want to support them to make decisions

Assuming you are progressing with supporting the individual's decision making then your approach should be:-

- Stay calm, have patience
- Build trust
- Use touch
- Maintain eye contact, be on the same level as the individual
- Have open body gestures, smile.

- Be matter of fact and relaxed
- Remain objective – ensure you are not inadvertently influencing the person's decisions by your words or gestures.
- Speak at a steady rate and normal volume
- Make sure your comments/questions are clear /unambiguous
- Use language the person understands
- Use short sentences
- If the person is struggling for words, do not be tempted to offer them a range of options hoping one of these may be the one they are searching for
- Listen actively, be observant – a change in the person's body position or facial expression may indicate something different to the words they are conveying.
- If you don't understand apologise and ask the person to repeat it.
- Check your understanding of what they have said by repeating back and rephrasing what you believe yourself to have heard / understood.
- Be alert to the person's emotions, acknowledge these.

The process

- Offer only as much support as is needed
- Explain things in simple terms,
- Break the matter into 'bite sized chunks, offer the person choices/options.
- Focus on one decision at a time, don't expect more than a couple of decisions to be made within the same time frame.
- Use, and encourage the person to use, simple gestures if this helps, e.g. thumbs up, down, pointing, head or eye movements, mimes,
- Use drawings, pictures, recordings etc if this will be better for the individual than words, or will complement the words.
- In any event, keep paper and a pen handy, be this for you or the individual
- Writing down key words can assist with the focus of the conversation
- Writing down choices can assist
- Will past examples assist?
Has the person had to make a decision of a like nature previously which you can discuss with them? Although remembering that circumstances can change and just because one made a decision one way in the past does not mean that one will make that same decision on another occasion.
- Can someone else help?
No one person has the monopoly on supporting another's decision making - even if this person is appointed as their attorney, or guardian. There may be others who can assist, for example a long-term friend or a daughter rather than a son, if they have had closer dealings with the parent over the years in respect of matters similar to the one on which a decision now needs to be made.
- Can it wait?

As has been touched on above, a person may be better able to make a decision on some occasions than others; if they are struggling today can the decision wait until later / for another day?

Once a decision has been arrived at the supporter should:

- Respect the person's decisions.
- Facilitate action, if required, to allow the decision to be met

The PANEL Approach

A recognised, human rights based, approach is that of the PANEL model, which effectively summarises all that has been said above.

- Participation – people should be involved in decisions that affect their rights
- Accountability – there should be monitoring of how people's rights are being affected as well as remedies when things go wrong
- Non-discrimination and equality – all forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised
- Empowerment – everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives
- Legality – approaches should be grounded in the legal rights that are set out in domestic and international law.

Best Interpretation Decision Making

Sometimes, no matter how much one optimises the decision-making environment and offers every support the person will not be able, on that occasion, to make a decision personally. You may then have to make a decision for that person – this should be a decision which is the best interpretation of the decision they themselves would have made – it is not the decision you think is right. Do not confuse best interpretation and best interests.

Supported decision making should be attempted first on each occasion. Do not assume because the person typically cannot make certain decisions that they will not be able to make that decision today and move straight to making that decision for the

person, even if it was a best interpretation of the decision they themselves would have made.

- What are their current wishes?
- Can we glean anything from current behaviours? Is their mood, their tone or pitch of voice, their attitude, even their physiological responses telling us anything about a preference?
- What would their past wishes have been? Can we draw anything from their approach to similar decisions?
- Is there a Statement of Wishes? Increasingly people are making a statement of their wishes and feelings which may assist with best interpretation decision making.
- Have we respected the person's rights, will and preferences?
- Can anyone else offer a view?
- Is the decision one which has clear benefit and is least restrictive? (see AWI principles Fact Sheet)
- Ensure you record the process, especially if the person's wishes cannot be established or the views of someone involved are not going to be followed. Records should use UNCRPD and AWI terminology e.g. why it would not be of benefit to the individual to do X. Or that Y is of lesser restriction so will be the path of choice.