

Rights, Will and Preferences Fact Sheet

Introduction

When dealing, in any way, with a person who has any level of intellectual impairment, including a complete loss of mental capacity, there is a requirement of us to respect that person's human/legal rights, their will* and their preferences.

*In this context "will" means the person's motivation, determination, intention or drive. It does not refer to any other form of 'Will', for example a legal bequest on death, or a living will.

Rights

There are a range of legal rights that any one of us are equally entitled to, without discrimination, no matter what our nationality, place of residence, sex, nationality or ethnic origin, colour, religion, language, or any other status.

Examples would be right to life, liberty, freedom of opinion and expression, right to education, to equality, to a fair trial, to privacy, to family life, to freedom of belief and religion.

These Rights are guaranteed by law, in the forms of various Acts, treaties, conventions and principles. Human rights law is a vast, and extremely complex, subject; it is not the intention of this Fact Sheet to give you, even an abridged, tutorial on this.

So, what do you need to know? That a person with cognitive impairment, even if this is total incapacity, loses none of their human rights and that the UNCRPD¹ requires us to respect these rights when working with, or for, that individual.

Will and Preference

In many references you will see 'will and preference' linked together, as if they are a single entity. It is important to remember that they are distinct.

¹ United Nations Convention on the Rights of Persons with Disabilities

Will is, as the dictionary definition would suggest, a sense of determination, a drive, a motivation, an intention.

Preference is a choice, a partiality.

A will, or preference, can be expressed in many ways e.g. words, tone of voice, behaviour, mood, posture, facial expression, eye movement, self-harm; some of these are intentional, some may be unintentional. The expression [of will, or preference] may be in an uncontrolled physiological response eg increased breathing rate, headache, needing the toilet more frequently, or being sick. You may need to watch and listen carefully to recognise a will, or a preference, being expressed.

Respecting will and preference in practice

The requirement is for us to 'respect' a person's will and preferences (as well as their rights). It is the person's views which must be central to decisions that we make – you may wish to read the sister leaflet to this on Supporting Decision Making.

To 'respect' does not mean there has to be unqualified deference to the person's will and preferences, i.e. that we have to go with whatever the person's will and preference is, unquestioningly; but their views cannot be ignored. We have to give genuine consideration to the will and preferences of the person, and as far as possible give effect to these.

Best Interpretation decision-making

There may be occasions when, despite every support, the person is not able to express their will or preferences on a given matter. If a decision must be made, now, ie the decision cannot reasonably be deferred, then one has to determine what the best interpretation of the person's preferences may have been.

To do this you will need to use a range of measures, for example.

- Knowing of, or asking about, past decisions of a similar, or comparable, nature.
- Knowing of, or asking about, relevant past expressions of will and preferences.
- Knowing of, or asking about, relevant past behaviours.
- Knowing, or asking about, the person's values and beliefs, so that a best interpretation decision can respect these.
- Reviewing a Statement of Advance Choice, if one exists (there is a separate information sheet about Advance Choice statements).
- Talking to trusted family, and friends.

- Obtaining information from other sources, where available eg a will.

It is appropriate to take account of the impact of the decision on others, eg on unpaid carers, or others who may share a home with the incapable person.

Any decision based on best interpretation should also respect the principles of the AWI (there is a separate information sheet on the principles).

When rights, will and preferences conflict

Having said we must respect a person's right, their will and preferences there will be occasions when this presents a challenge.

Perhaps

- Current preferences do not align with long held past preferences or maybe,
- Their current preference and current will are at odds. For example, someone may wish to see a family member (this is their preference) but when that person visits, they get agitated and refuse to engage with them (this is an expression of their will) or maybe
- The rights of one person conflict with the rights of another; for example a person who wishes to live in a particular accommodation (which is their right) but who endangers others they live with by their behaviour (the other person has a right to live safely)

There is no easy answer when rights, will and preferences conflict like this, and no single piece of advice that can be given, yet we must manage such conflicts.

Managing conflicts

The first thing to consider is whether a compromise is possible. Is there a different way of achieving the same end result in a way which is acceptable? For example, using the visit scenario above, would a meeting in a neutral venue, or at another time, or with another person present make a difference?

Sometimes though, it is just not possible to eliminate conflicts; then it is a case of making sure you have a correct and comprehensive understanding of the full situation, from which you have to reach what you believe to be the best compromise decision in the circumstances.

Am I clear what the central issue is and what outcome we need to reach?

In conflict situations it is easy to lose sight of the key issue; ensure you are clear about exactly what outcome you are trying to achieve.

Have I fully supported the person to make their own decision?

Are you satisfied that you have fully supported the person to offer their own views? Do you need to involve anyone else, including, for example, independent advocacy, to ascertain the person's views impartially?

Is the individual free of undue pressure?

Is the view being expressed by the person their 'unencumbered' view, and are you sure they are not saying what they think they should say? Ensure that they are not being influenced by you, by someone else, or by the situation into thinking they have to say a certain thing.

What are the person's rights in the given situation?

Are you clear what the person's rights are? Have you given more than mere consideration to these? Are you going to be able to respect these? If not, have you got a clear rationale for disregarding their rights?

What is the person's own view on the matter? What is their preferred outcome?

Are you clear what the person's own will and preferences are? Have you given more than mere consideration to these? If you are not going to be able to respect these, do you have a clear justification?

What is the best interpretation of the person's views?

If the person has not been able to offer their opinions, do you know what the best interpretation of their views is?

Do you need to know anything more about the circumstances or the situation?

Make sure you know all you need to know; do not make the mistake of working with only a portion of the relevant information.

Are you clear of time frames?

Do not feel pressured into making a decision under the false assumption of a tight time frame. Do you have longer than is assumed? If not, can you negotiate longer – to allow for a properly considered decision? If yes, be clear how long may be required for this.

Have you reviewed the position objectively?

Challenge yourself on this; make sure your own values are not, even inadvertently, creating the conflict. Have you asked the views of others? Can someone else offer a view which may help?

Are all possible options under review?

Ensure you have thought laterally about all possible options. Do not make the mistake of going with the one which seems the most viable, or obvious, or even the

only one, without first having considered whether there are others. It may be obvious to you that these other options will never be viable solutions, but an objective, systematic review would include them anyway, even if only to exclude them in the end.

Have you conducted a review of each option?

For each option consider:

- What are the views of the person – on each option?
- What are the views of others – on each option?
- How would this option benefit the person, and is this option in their best interests?
- Would there be any risk or detriment to the person from this option?
- Is this the least restrictive way of achieving the outcome needed?

Is there any compromise option?

Is there an option which the person would tolerate, even if it's not ideal? This still has to be a viable solution. It may be that it presents a short-term option while time is taken to consider the longer-term, or broader, options.

Have you sought the opinions of all relevant people?

Ensure you have not omitted a relevant player; the views of all relevant people involved need to be considered.

Are there wider things you need to consider?

It is appropriate to consider wider things in such a review; for example the costs, or the impact on, or risks to others that any of the options may present.

Is there anything else you need to consider?

This is a generic template: is there anything particular to your current case/situation that you need to consider before reaching any conclusions?

Would it be wise to consult someone else or obtain authority before making a decision?

Do you wish to, or need to, run your proposed decision past someone else, for example the local authority, the Office of the Public Guardian, a lawyer?

Have you made a clear action plan?

Am I clear about who is doing what, in what time frame, when this will be reviewed etc.? Are all relevant others also clear about this action plan?

Whom do you need to tell?

When you have reached a decision on the way you wish to progress the matter, make sure you advise everyone who is relevant.

Have you made a comprehensive record?

When you have completed this formal assessment, you are advised to make a clear record of all the things you considered – discussions, actions, your rationale for your decision etc. – as this will be of great assistance should there be any challenge to why or how you arrived at the decision you have taken.