

Our Participation Promise

Background to the development of this poster

The Our Participation Promise poster was developed as part of the Managing My Way project – a project set up to look at ways in which disabled children and young people could be given increased choice and control over decisions which affect their health. Disabled children and young people lag behind their non-disabled peers in the area of participation and we recognised the need to bring together material specifically developed for them. This material can be found on the following website:
www.councilfordisabledchildren/managingmyway

Involvement in decisions and giving consent

Disabled children and young people will be able to participate in decisions in different ways depending on their age, impairments and level of understanding. Participation should be facilitated at whatever level is appropriate for the individual child or young person and no one level should be given greater importance than any other level.

Gauging the level of participation:

For each individual child or young person you will need to gauge at which level they are able to participate:

- Able to express preferences through their non-verbal behaviour/communication that needs to be understood and taken into account

- Able to understand information
- Able to express a view (with or without help from another person)
- Able to take part in discussions leading to a decision
- Able to be the main decision maker.

Assessing ability to make decisions:

Some disabled children and young people are able to fully participate in decisions and will be able to take a great deal of control over their health treatment. They will be able to consent to treatment and examination. In assessing a child or young person's ability to make decisions it is useful to use the factors outlined in the Mental Capacity Act (2005) and detailed in the Department of Health guidance on consent:

- Does the child or young person have the ability to understand and retain the information on which the decision will be made?
- Does the child or young person have the ability to weigh up the different options and reach a decision?
- Does the child or young person have the ability to communicate the decision which they have made?

Providing appropriate support:

In order to give the child or young person the maximum opportunity to be involved in decisions:

- You need to know how they communicate and their level of learning disability or cognitive impairment.
- You need to provide information in formats which are appropriate to the child – using pictures, symbols, photos – depending on which method is used by the child.
- You need to give the child the opportunity to express their views in methods which may not be limited to the use of language.
- You need to provide, if necessary, assistance through an independent person to give the child time to explore different alternatives, help to talk through and weigh up the different options and assistance with alternative methods of communication.

Making ‘best interest decisions’:

Some disabled children and young people who have very severe cognitive impairments or learning disabilities or who are very young will be unable to make decisions or give consent. Decisions will need to be made by health professionals working together with parents or other family members. Decisions made on behalf of disabled children and young people must always be made in the best interests of the child – the ‘welfare principle’ will always apply.

For adults who lack capacity the process of making ‘best interest’ decisions is more well developed and staff working with children should consider using similar processes to ensure that decisions are made in which the children remains central. It is useful to:

- Record your thinking and conversations with parents
- Consider a range of options – discuss what the option looks like through the eyes of the child
- Discuss the benefits and drawbacks of any decision.

Best interest decisions should come out of a combination of knowledge – your medical knowledge and the parent’s knowledge about the child

Useful Guidance

ACT (2011) *A parent’s guide: Making critical care choices for your child*

BLISS (2011) *Making critical care decisions for your baby*

Department of Health (2009) *Reference guide to consent for examination and treatment*

General Medical Council (2008) *Consent: patients and doctors making decisions together*

General Medical Council (2007) *0-18 years: guidance for all doctors.*

Please put the Our Participation Promise poster up in your clinic rooms