

Supporting meaningful participation in decision making for children with Severe and Profound and Multiple Learning Difficulties

Why is supporting participation in decision making important?

- Because we have to- SEND Code of Practice 2015 and Articles 12 and 13 of the UN Convention on the Rights of the Child tells us that
 "Children have a right to receive and impart information, to express an opinion and to have that opinion taken into account" and that this may look very different for children with SLD and PMLD, and their views should be "given due weight according to their age, maturity and capability"
- Children with SLD and PMLD are often users of a wide range of services, and their views are essential in improving the fit between services and children's needs.
- Disabled children are 3 times more likely than their non-disabled peers to experience abuse (NSPCC, 2014). Effective participation should contribute to a culture where it is safe for children to express their views and have those views taken seriously.
- It is a key part of learning for children with SLD and PMLD, developing communication, choice making and expressing preferences.
- Effective participation should support professionals to plan better and to support preparation for adulthood, resulting in higher quality Education Health and Care Plans and provision.
- It works! "Seeing him at the beginning of the meeting is like 'okay. This is why we're here!'- and it's worth it."- Parent, Tower Hamlets, 2017.

How can we develop and support participation for children with SLD and PMLD?

- It is important to gain meaningful consent from children about participation, and to ensure they understand what they are consenting to. It is equally important to feed back to children about what will happen next.
- If participation happens regularly, rather than as a one-off event, children will develop their skills in expressing their views, and will begin to see others acting upon them. There are plenty of opportunities across the day for children with SLD and PMLD to make choices, and this should be a key part of their learning.
- It will often be necessary to reflect back what has been expressed by children with SLD and PMLD to check our own understanding and show children that we have heard.
- Children may not always tell us what we want to hear, but it is essential that their views are respected. With this is mind, care should be taken when deciding who is the best adult to support the child's participation.

Resources to support participation in decision making

It is important to choose the right resource for the child's understanding and communication level.

Video, edited using simple software such as iMovie	Talking Mats Can be a trademarked resource or a version created by adults using own symbols.	Photo sorting Set of photographs for child to place under positive/neutral/ negative symbols	About Me bags/boxes Objects selected by the child to express preferences
Our Story, a free app enabling children to import photos, videos, recorded speech and text.		negalive symbols	preferences

A suggested structure for supporting participation in decision making

Check consent to meet with you.
Have room set up with furniture and resources ready.
Explain your role in simple terms using signs/symbols to reinforce key words – e.g. "to find out what you like, don't like and think is okay". Check with child what yes and no look like for her/him, and check consent to work with you.
Explain the purpose of the session e.g. "to find out what you like and
don't like to help the grown-ups plan for you to do more of what you like"
Use signing/symbols to reinforce the key words.
Let child know who the session will be shared with and check consent.
Ask child: "Are you happy to do this with me today?"
 Tell the child, using signs and symbols to support: That s/he can stop whenever s/he wants- check what "Stop"
 looks like for her/him and check this by reflecting back. That she can tell us if s/he doesn't understand- check what this
 Indistre carrier os insyne doesn'r onderstand- check what this looks like as above.
 That s/he can tell us if we get it wrong- check what this looks like as above.
Evaluate how the session went, and identify key information to share with others.
Provide feedback verbally or in writing/pictures using simple language
and visuals to summarise what we did, congratulate the child on
her/his participation and let her/him know what will happen next.

January 2018