

Listening to children or young people with complex or challenging communication and/or understanding

First principle – this takes time!

For children who have difficulty expressing choices or opinions it is especially important to work hard to involve them in decisions which may affect them as they are unlikely to be able to influence such decisions without substantial support.

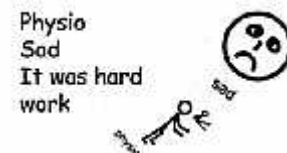
It will be important to establish what the communication and understanding challenges are. A sample communication needs form is available in the toolbox which can be used to work with the parent/carer to discern the specific challenges and modes of expression for that child.

Talking mats - for those who use symbols



This approach was used with one child in a consultation about respite services. The child needs to be familiar with using a happy and an unhappy symbol. A mat is then used with a division between happy and sad. Children can then place symbols according to how they feel about them - happy or sad. To test if the children are understanding what they are doing, throw in a few red herrings, things you know they definitely will or won't like.

This method was adapted for the Specialist Health services consultation when children had symbols for the services they accessed and then chose from a series of [Makaton](#) emotion stickers how they felt about them.

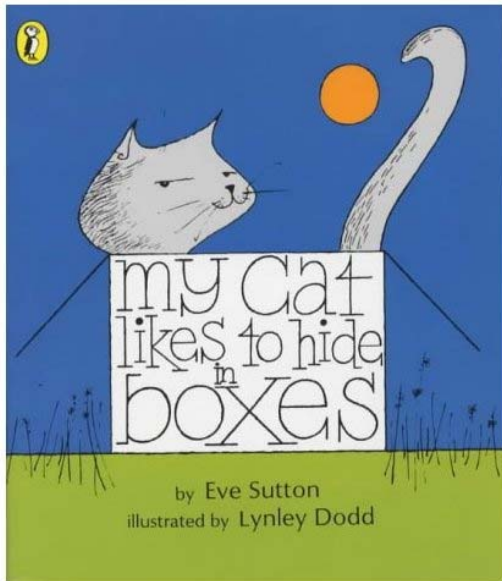


Using a Communication Aid

Where a child uses a communication aid such as a switch or other aid, this can be used to allow the child to express themselves. It will be important to take the time to establish a dialogue with the child using the aid so that the child and investigator are able to communicate effectively.

For example, Vicky, who was able to use a switch to make choices, ("I want this one") was able to use the switch to express a view on her respite care. This was done by first of all having several sessions where the switch was used to allow Vicky to choose which

story books she wanted and then to participate in the stories by joining in repeating lines using the switch.



Vicky's Favourite story with repeating line

Once this system was well established and clearly enjoyed and anticipated by Vicky, a story was made up from the known interests of Vicky (as shared by her parents and carers) of a princess who looked beautiful and wore pretty things and a naughty brother who kept getting up to mischief. The story had repeating lines about things the Princess might like or not which followed the question "Does Princess like this?". This established that the switch could be used to express likes and dislikes, using rhyming couplets for which Vicky had shown a preference.

"I like it, I like it, I like it you see; this is very nice for me"

Or

"No, no, no, I don't like it, not one teeny tiny bit."

Vicky was then asked about her experience in respite care. The switch was first of all set to saying "I like it.." and the whole routine of an overnight stay was gone through and at each stage the question "Does Vicky like this?". Vicky was asked to only press the switch if this was something she liked. The switch was then set to the "No, no, no.." and Vicky was asked to only press the switch if she did not like it. This process was repeated over several sessions in different settings (at home and in respite care setting). From this it could be seen that Vicky used the switch consistently to express the things she liked or did not like about her routine in the respite setting.

For children with complex needs

For some children with more complex needs, their sole means of communication might be a flicker of eyes, a variation in sound made, a gesture. In order to find out how positive or negative an experience is for such a child, it will be necessary to make careful observation having established what each nuance of expression might mean. This can involve using all of the senses available and offering the child both things likely to be enjoyed and things likely

to be rejected, so offering both pleasant and unpleasant smells, sounds, textures to touch, bitter, sweet, sour tastes and so on. By doing this, careful observation can be made of expressions meaning anything from pleasure through indifference to strong dislike. If this is done a few times at different sessions and times, a pattern should emerge to establish what different expressions mean. ([MENCAP Listen UP](#))

Often these children will not be able to express a view on anything that is not happening in the present, so careful observation of the child in different circumstances at different times of the day can indicate the child's degree of pleasure, acceptance, rejection of the daily routines and activities in which he/she is involved. This method was used with a young person accessing respite care and indicated preferences in personal care about things like the bath being a better option than a shower, a dislike of the hoist, pleasure in hearing particular music and so on. While something unpleasant like being in the hoist may be unavoidable, it might be that by trying it with something more pleasant, like music playing, it might become a less stressful activity.

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