Serena [not her real name], a young woman with quadriplegic cerebral palsy and PMLD, was involved in a research project around learning.

Serena's teacher (who knew her well) and the researcher judged that videoing her responses to an intervention, which could then be reviewed afterwards by her teacher and teaching assistants together, would be the best way of beginning to understand more about how the young woman learned.

Serena had no means of formal communication, but the teacher and researcher decided that the young woman's response to seeing a digital video of herself would be an acceptable indication of whether she was happy to be videoed. The researcher took a short piece of video of Serena, and then showed it to her in the viewing pane of the video camera. When she saw it, Serena gave a broad smile. The researcher and teacher interpreted this as assent to being videoed. This was repeated on each occasion when Serena was videoed.

Comment:

While Serena could not understand the concept, purpose, or her part in the research, her parents felt that there would be benefits for Serena through involvement in the research. However, although Serena could not give informed consent, she was able to express her emotions reliably which the teacher (who, importantly, knew her well and could interpret her responses) used to assess whether or not she assented to being filmed. This was not a one-off response. It is important with children and those with learning difficulties that their consent/assent to taking part in the research is reaffirmed at each session.