Parent-delivered interventions used at home to improve eating, drinking and swallowing in children with neurodisability: the FEEDS mixed-methods study

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Plain English summary

Some young children with disabilities, such as those with cerebral palsy and autism spectrum disorder, have difficulties with eating, drinking and swallowing. Many strategies are employed to help with these difficulties (e.g. ‘Positioning’), but we need to know more about which ones work best.

We wanted to find out about the strategies parents use at home to help their children with eating, drinking and swallowing difficulties. We wanted to understand what is already known about the strategies that are available now and if children are getting the right help. We wanted to find out if doing more research would tell us which interventions work.

We looked at what has been written about the ways in which parents help their child to eat, drink and swallow. We discussed this information with parents and health professionals. We developed a survey to ask what parent-delivered strategies are recommended by NHS professionals, which strategies parents use and how we would know if things had improved. We discussed the findings with parents and professionals.

We then used a different type of survey. Parents and professionals were asked which strategies were most important and what they would most like to improve. We then held workshops to hear parents’ and professionals’ views on what we had found and to agree on how we would organise future research. We discussed some of the findings with young people.

Research about these strategies and how to measure improvements in eating and drinking is of poor quality. A wide variety of strategies are used: 19 strategies were thought to be the most useful by parents and professionals. Parents and professionals agreed on 10 areas that they would most like to improve. Both groups thought that it was a good idea to have a ‘toolkit’ of strategies so that they could choose the right strategy at the right time.
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This report

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