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BACKGROUND

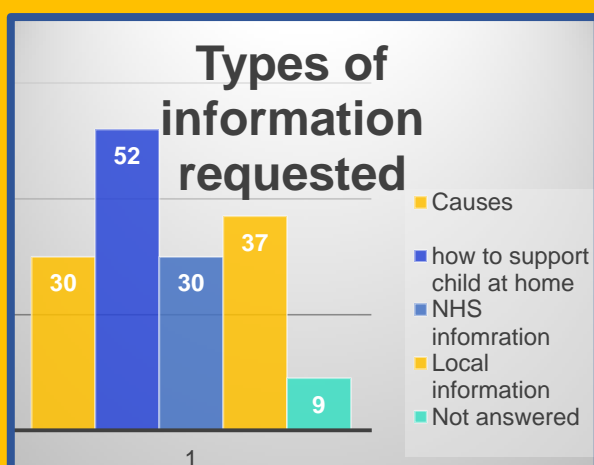
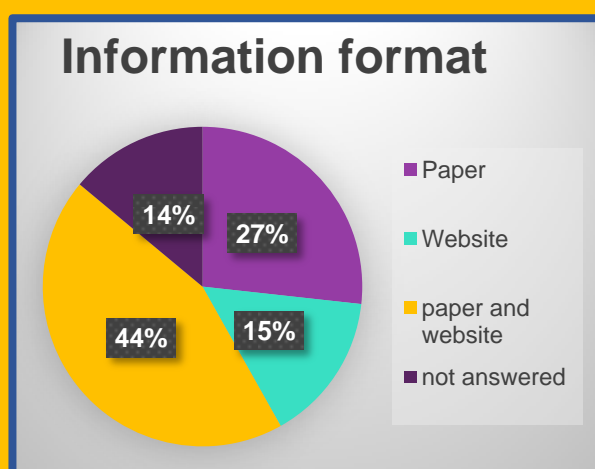
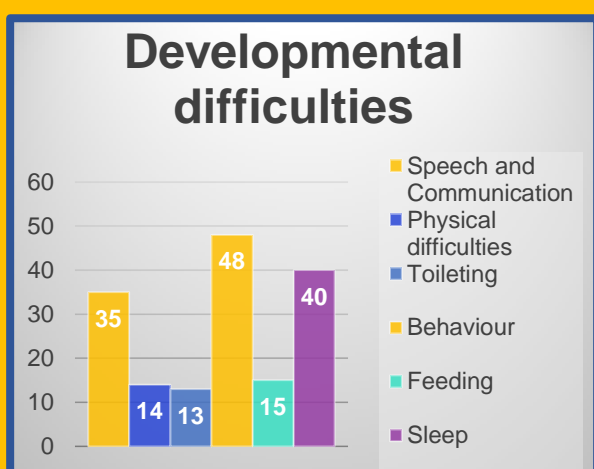
Global Developmental Delay (GDD) is a diagnosis given to young children (usually under 5 years) who have significant delay in reaching milestones in two or more developmental domains. While, increasingly, there is information and support for the care-givers of children with other neurodevelopmental conditions, little is available for families of young people with GDD. We sought to co-produce a leaflet for families of children given this diagnosis.

METHODS

Using an iterative co-production methodology¹ in partnership with two local third sector parent-carer organisations, a survey questionnaire was designed to seek information about the support needs of families with a child visiting a Child Development Centre (CDC) with a variety of different developmental difficulties. The survey was completed by 70 families.

Identified themes were then discussed with the parent carer organisations and used to draft the content and format of a leaflet aiming to support families of children with Global Developmental Delay.

RESULTS 1



RESULTS 2

Focus group themes: Parents felt diagnosis of GDD was unhelpful and confusing, and for some families misleading and detrimental.

Focus group themes



CONCLUSION

- The project demonstrated the importance of co-design in developing relevant and useful information resources for families.
- Our literature search indicated that there is a reasonable amount of information for parents and carers on the internet but it is hard to locate. Most parents, regardless of their child's diagnosis wanted more information about providing support, particularly at home.
- The focus groups raised some important concerns about the 'Global Developmental Delay' diagnosis. This may not only be unhelpful and confusing but in fact detrimental for some families.
- To demonstrate the findings nationally, an abstract has been submitted to the Royal College of Paediatrics and Child Health (RCPCH) annual conference.

Reference: ¹ NIHR INVOLVE (2018). *Guidance On Co-Producing a Research Project*. 2018. www.invo.org.uk