

The F-Words in Childhood Disability: A Values Statement for Children, Families and Service Providers



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Background

- The WHO's International Classification of Functioning, Disability and Health is increasingly being used as a conceptual framework to plan goals and points of entry in developmental interventions.
- With children, young people and their families being central to the decisionmaking process, how can the ICF be adapted to be user friendly and accessible to a wide range of people?
- Building on the ICF, the paper "The F-Words in Childhood Disability: I swear this is how we should think" transforms the domains within the ICF into ideas that are fun and easy for children and young people, families and service providers to remember and use.
- Since the publication of the 'F-Words' paper, our collective of clinicians and parents has continued to discuss the F-Words.
- One outcome of these collaborations has been an 'F-Words Agreement'. This informal 'contract' between children/young people and adults involved in their care focuses on the values underpinning interventions, namely:

The right to choose what is FUN.....The importance of listening FAMILIES..... respecting the way 'stuff' is done (FUNCTION)......

Methods

FUTURE

FUNCTION FUN FRIENDS FAMILY FITNESS

- •We propose that by using these 'F-Words', we can take a novel approach to talk about what really matters to the child/young person and their family.
- To do this we have developed a simple yet effective way of giving children/ young people and their families a voice in therapeutic encounters.
- •This statement of values can be personalised to the individual child/family.

Aim

To promote discussion about these ideas as a way to give an authentic voice to families as well as clinicians

Results

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F-WORDS AGREEMENT Please consider these things when we work together FUNCTION - I want to do stuff! It may not matter if I don't do it like everyone else! FAMILY - They know me best and I trust them to do what's best for me. Listen to them. Talk to them. Hear them. Respect them...... FITNESS - Everyone needs to stay fit and healthy and I am no different. I might need to use different ways of getting fit and staying fit and need help to FUN - Whatever floats my boat!!..... FRIENDS - to meet and get to know, have fun with, to learn with, to grow old FUTURE - The Future Is Now - Tomorrow is what I make of today. I don't want opportunities to pass me by. Help me achieve what I can today. Thank you McMaster University

F-Words Agreement Can Be...

- · ... used as an ice-breaker by families who are new to 'the system' and feel overwhelmed.
- ... personalised with specific details of how the child/young person wants to 'do stuff'.
- ·... a working document updated as needed.
- ·... translated by clinicians into ICF language to assess and monitor children's progress

Conclusion

- The ideas in this poster have already empowered many parents to express their endorsement of this values approach.
- We welcome the opportunity to reach more parents, and to develop collaborative projects with colleagues who want to use the F-Words Agreement and would be willing to share both their individual adaptation of the Agreement and assess its impact on children and families.
- We invite people to contact us (details below) if they are interested in using this Agreement and a simple data gathering form to collect information about its use over a one year period
- We will share findings in future meetings.

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The F-Words in Childhood Disability: Swear this is how we should think. Rosenbaum PL & Gorter JW. Child: Care, Health and Development. Jul;38(4):457-63.