

# The COVID Time Capsule Project: Children with Disabilities and Their Parents as Active Participants and Partners in Research



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# Who Speaks for Families?

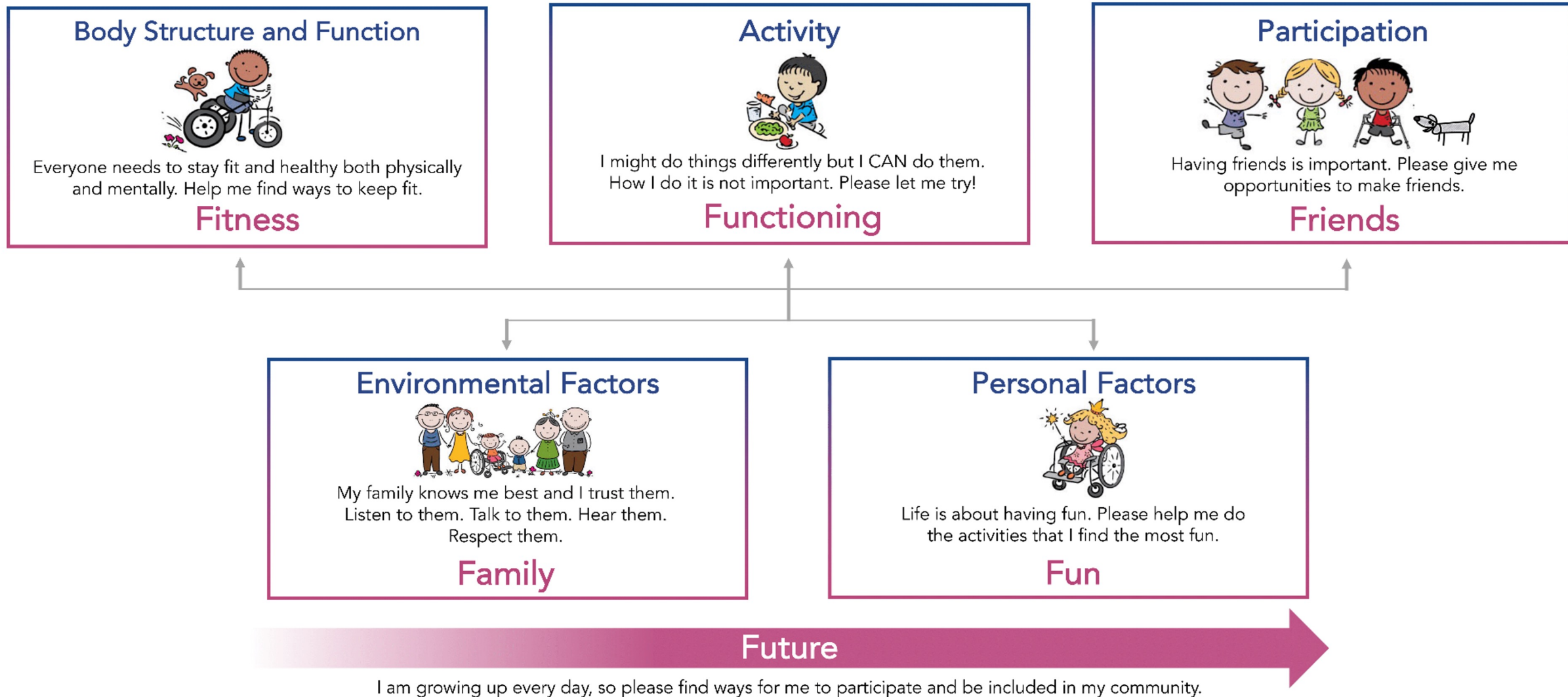


- Often from the perspective of parents
- Child/youth engagement becoming more common
- Disabled children's voices are underrepresented
- United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (2006):  
“Children with disabilities have the right to express their views freely on all matters affecting them”...” and to be provided with disability and age-appropriate assistance to realize that right”

# The Project: Covid Time Capsule

- Goal: learn about disabled children/youths' and their families' experiences during Covid to identify services and supports that are needed moving forward
- Integrated Knowledge Translation approach (4 children with disabilities and mothers involved from the beginning)
- Explore children/youth's experiences in different domains of life: family, friends, school, fun, fitness, and future using a child/youth-friendly approach
- Visual component > Interviews > Survey > Recommendations > Knowledge Translation materials

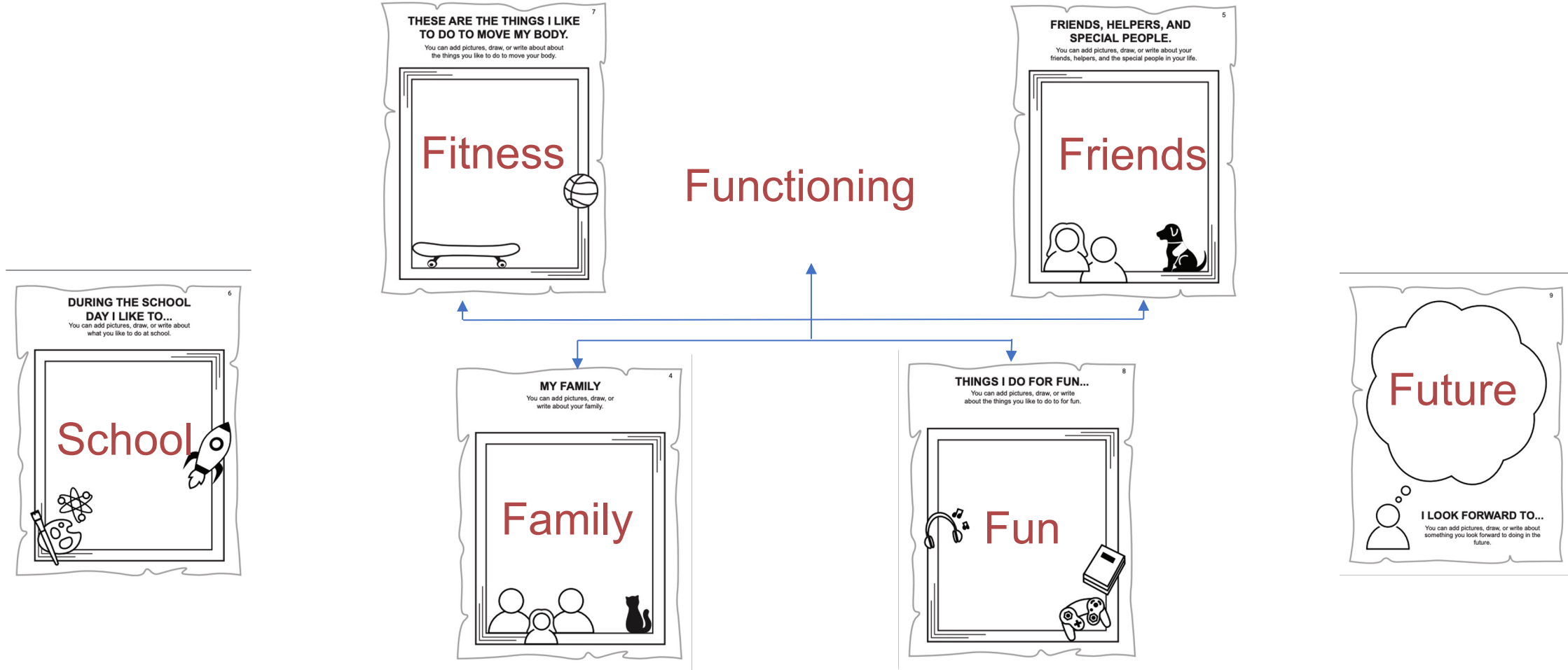
# The ICF Framework<sup>1</sup> and the F-Words<sup>2</sup>



For more information visit the F-words Knowledge Hub:  
[www.canchild.ca/f-words](http://www.canchild.ca/f-words)



# The Covid Time Capsule and the F Words



# How We Engaged Youth

Meet > Consent > Visual Worksheets > Interview with Child/Youth > Interview with Parent

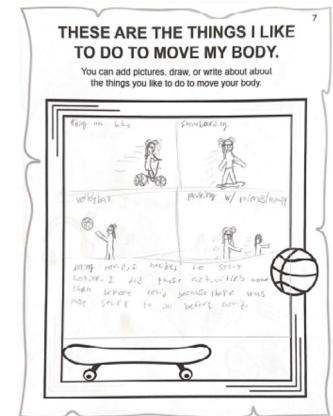
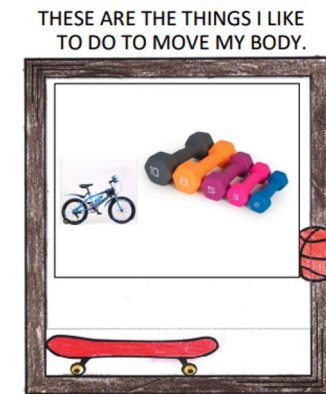
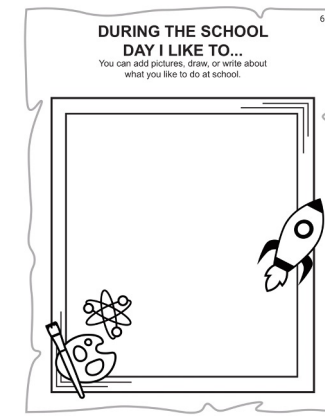
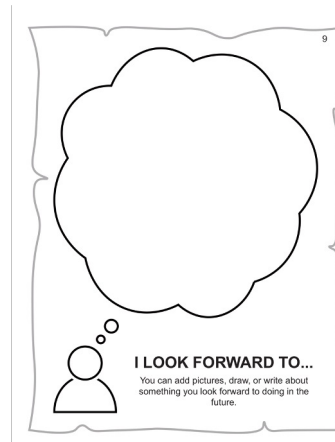
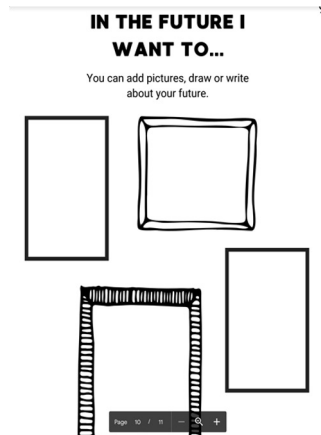
Child/Youth Participants/ Junior Researchers	Junior Researchers
Initial contact with parents	short, interactive meetings
Describing research to youth	Social time
Consent from child/youth needed to move forward	2-3 adult team members besides parents
Flexibility/Choice	Other opportunities to give feedback
Parents in background to support as needed	Compensation/Appreciation
Friendly chat – no right or wrong answers	

# The Difference

## Logo

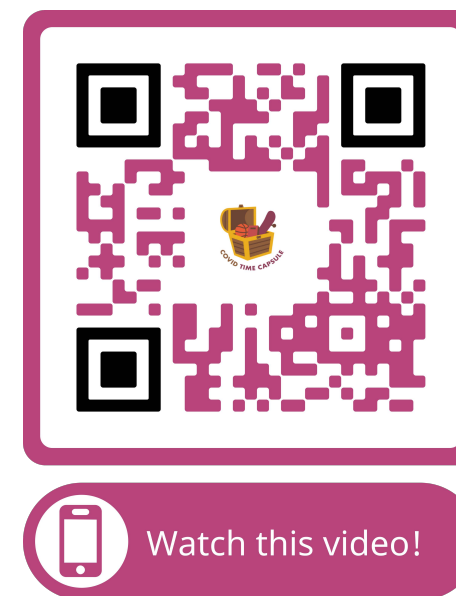
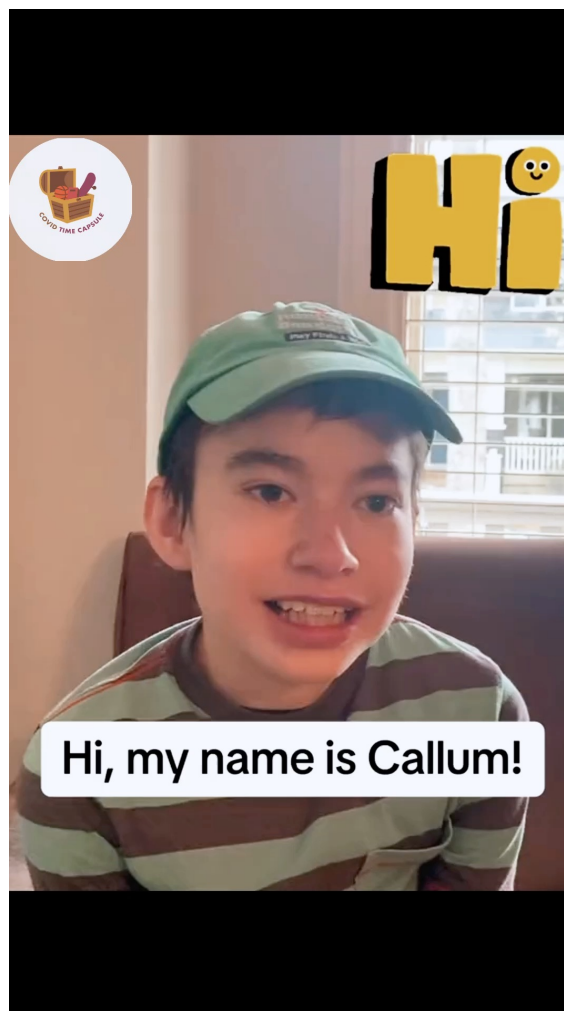


## Visual Worksheets





# TikTok – Project Recruitment





# Results

- Child/youth and parent interviews complemented one another
- Varied experience – COVID disrupted everyday activities and supports and affected mental health, but allowed for more time together and virtual healthcare, education, and activities
- Parents filled in the gaps in supports, many reduced work to do so
- COVID worsened a system that was already not meeting the needs of families
- Going forward, families need:
  - Flexibility
  - Social connections/supports that are constant and reliable
  - Comprehensive and holistic “wraparound” supports

# Parent Perspective of Process – Participants

“I was surprised more like the layout of things. I was surprised that she was able to express — because she always has a very, very hard time just with words, with determining how she feels and what she likes and it was way easier for her to decide on that with this art approach.”

“I feel from my point of view knowing how he communicates, I think he was very engaged, and I think he really did the best he could. It’s hard to gauge it when you don’t know him and you haven’t seen how he communicates, but I think it’s obvious that he’s cognitively aware. He laughs and smiles and jokes and you can see he is aware of things, where I think some people kind of question that sometimes. I think it was pretty clear in this interview with him that he does get what’s going on and I think from knowing him I think he did a good job.”

# Partner/Collaborator Perspective

## Parent Partner:

“This project gave my son a voice and a purpose. He could contribute to something he was interested in with his peers. It is an amazing experience!”

## Youth Collaborator:

“I get paid to share my opinion and create cool stuff. Plus, I make way more money than delivering papers!”



# Key Messages

- Obtained a fuller picture of the family experience and needs by having both parent and youth participants
- Youth need a flexible approach
- Taking time to build relationships is essential
- Planning and clear communication are key
- Youth collaborators were integral to the study
  - As one youth collaborator said, “The project is definitely better because of us.”

# Acknowledgements

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# Keep in touch with us!



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