



## Co-designing Accessible Information Resources With and for Families: Does it work?

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# The catalyst for the project

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1 – 3% of children under the age of five years have a diagnosis of Global Developmental Delay (GDD) (Levy et al., 2011) – a holding diagnosis

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Families with children with disabilities consistently emphasise their need for information (e.g., Al-Kandari, 2014; Brown et al., 2012; Dew et al., 2013), with the internet seen as a major source of information (Johnston, Tracey et al., 2013).

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Australia-wide research found that parents want information that is easily accessible, jargon free, in multiple formats, unbiased, evidence-based and delivered by experienced professionals and other families in similar situations (Tracey, Johnston, et al., 2018).

# The Living Well with Global Developmental Delay project:

AIM: To develop accessible, evidence-based information resources for young children and families living with GDD

Initially a 3 year project – began in 2020 and due to end June 2026

## The project team:

Six researchers and service providers

Five parents and one grandparent who have a child who was identified as having GDD

# Why Co-design?



# Our approach

- Parents were invited to be part of the Working Group
- Given a gift voucher to cover attendance costs for each meeting
- On-line interaction only - families in 2 states; metropolitan and rural
- First meetings about getting to know each other and motivations for being involved
- ACTIVE advisors having input into what content should be included, in what format(s) and read and commented on drafts
- Research partners and ECI professionals write the resources – reviewed by team
- Working Group members write blogs and appear in videos if they wish
- Compact was developed to guide the interactions

# Guidelines for meetings

Our approach aims to create a shared community of practice in which all stakeholders have a role in knowledge creation. Our ethos is aligned with the fundamental values of co-production in emphasising genuine power-sharing and a democratisation of relationships between the different individuals and institutions involved.

## To do this:

- At the start, give everyone a chance to talk (in turn)
- Having video on is preferred but not mandatory
- During the meeting, ask ourselves: Are we listening? Are we allowing them to shape what we're doing? Are they having their views heard?
- Stress that it's a learning process for all of us
- At the end ask each participant, "Did we address the things that were important to you today?"

# Working Group's motivation to be involved

“To start with you find out your child has a delay, been diagnosed, you know, with an issue, it's a bit overwhelming, and you actually need people to guide you and say well, if you look at this resource....”

“I had no idea where to start.. I kind of questioned, I'm left with nothing, like where do you begin? What do you do?”

“I found it to be a really isolating experience.”

“I just had to rely on other people.”

“I don't want others to go through what I did.”

“If parents got the info because they're the ones, everyone's doing their own research and when you bring it all together you come up with all these different things... I get most of the research and info from parents... there's no one you can really call and ask where do I begin, you just don't know...but it would be fantastic to know that somewhere was that pathway from the moment that you're told that your child may have a DD and how can we support you, I think that would be ideal.”

“I was a bit lost for a while, it was a relief when I found the right person to help”

# Evaluating the co-design model

## Aimed to:

1. explore the parents' experience of co-design and
2. determine the impact of co-design on the outcomes achieved.

## Methods:

- research assistant, external to the project, gathered data on the parents' perspectives
- short questionnaire (12 questions with 4-point Likert scale – very unsatisfied to very satisfied)
- semi-structured interviews.
- researchers had access to deidentified data only.
- the minutes of the meetings held throughout the project were also analysed to identify the nature and extent of input from the parents.
- parents' input was mapped against the resources developed.

## Participants:

- 4/6 completed the questionnaire
- 3/6 were interviewed

Caution needed in interpreting the findings!

# Questionnaire data:

All responses were positive

The 2 questions which attracted the “lowest” mean scores (M=3.5) were:

- How satisfied are you with your contribution towards the GDD project?
- How satisfied are you with the value of your contribution towards the GDD project?

All participants reported that they:

- felt safe and supported to contribute to the co-design process
- had an equal voice, and that their contribution was given the same weight as other members

# Interviews

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- **Equal opportunity to share opinions:**
  - “In our meetings we were given the opportunity to share our opinions. Everybody was given the opportunity to voice their feelings or their thoughts on the information that was sent to us to go through and when we would meet at the next session, all that information was discussed, and everybody was given the opportunity to voice their opinion.” (P3)
- **Skills and experiences of GDD valued**
  - “I think my skills and experience were valued just by the fact that what I discussed is included in the resources. So obviously to me, they were valued, and they understood what I was trying to get across and transfer into the resources. Also, when we had our discussions and we brought issues up, they organised and look into the issues further and came back with some information that might help resolve the issues better.” (P2)

# Challenges of using and evaluating co-design:

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We were unable to attract parents from First Nations and CALD backgrounds to the Working Group

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All members of the Working Group were women, having men in the group would have been beneficial as would be including siblings

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Hearing the voice of those who have GDD would also have strengthened the project

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Time constraints of the Working Group

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Small numbers – how to encourage honest and open responses

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# Evaluating the resources produced:

Monthly search engine optimisation (SEO) reports tell us:

- Keywords are working well and bringing searchers to the website
- Averaging 700 new users each month
- Need to look at ways of increasing the amount of time people spend on the website

So:

- Building additional internal links within the site itself and building backlinks from medical and educational website to improve trust
- Prioritising content development, providing a glossary of terms for users (jargon remains an issue for families), a FAQ section to answer common questions
- Monthly blogs by parents, family members, professionals
- Use of social media – Instagram, LinkedIn

## Focus groups

Does the website meet the needs of families from diverse cultural and linguistic backgrounds?

- 6 focus groups (n = 40) – parents and caregivers from First Nations, Arabic, Chinese, Vietnamese and Middle Eastern communities (interpreters used when needed)
- Asked them to explore the website and comment on its usability and relevance as well as the usefulness of the UserWay translation and accessibility tool

### Key findings:

- seen as providing useful resources
- diversity of formats (blogs, written information, videos) liked
- translation tool *generally* regarded as accurate and worthwhile
- accessibility tool seen as helping those with lower levels of literacy

### BUT

- did not always see themselves represented in the website images
- want more culturally informed stories, videos
- want more interactive modules
- more practical support content
- want follow up to see their suggestions implemented

## Next Steps:

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Build more interactive modules (first one on family wellbeing currently being reviewed by our Family Working Group)

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Revisit all images on the website to ensure those visiting the site “see themselves”

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Develop more videos featuring families and professionals from diverse cultural and linguistic backgrounds

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Professional translation of some of the most used resources into 20 community languages

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Continue to engage with focus group participants who wanted follow-up (the First Nations groups were adamant about this) to ensure their ideas were incorporated and valued

# Final words:

“Proud, appreciated, thankful” (P1)

“Included, proud, hopeful” (P2)

“Valued, acknowledged, contributory” (P3)

**Please give three single words to describe how you feel about your role in the co-designing project:**

To see the website go to:

[www.globaldevelopmentaldelay.com.au](http://www.globaldevelopmentaldelay.com.au)

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# The website



Resources for you and your family developed by  
families, professionals and researchers

**TO HELP YOU LIVE WELL WITH GLOBAL  
DEVELOPMENTAL DELAY**

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