



Consumer and Community
Involvement Program



WAHTN

Western Australian Health Translation Network

enAble institute

'ALL ABILITIES'

COMMUNITY CONVERSATION REPORT



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MAY
2024

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ACKNOWLEDGEMENTS

Acknowledgement of Country

The Western Australian Health Translation Network (WAHTN) and Consumer and Community Involvement Program (CCIProgram) acknowledges the Aboriginal people of the many traditional lands and language groups of Australia. We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

Other Acknowledgements

We would like to express our sincerest gratitude to all the consumers and community members who attended the Community Conversation; your time, energy and contributions are all greatly appreciated.

Lastly, we would like to acknowledge members of the WAHTN CCIProgram team, Curtin enAble Institute and Curtin Involve teams for their diligent work in planning, promoting, and successfully facilitating the event.



BACKGROUND

The Curtin University enAble Institute launched in 2022, an interdisciplinary health research institute that focuses on conducting research that is responsive to the priorities and needs of the community. The Institute aims to conduct innovative research, in partnership with consumers, communities, industry, and government, that enables the implementation of evidence-informed solutions that promote health, wellbeing, and quality of life for people of all ages and abilities. The Institute's approach to research emphasises consumer and community involvement with consumer advisory groups embedded into the Institute's governance structure and for each individual research project. The Institute focusses on building capacity for consumer-led translational research and offers research training that supports consumers to advance their understanding of research methods.

The Curtin enAble Institute and Curtin Involve team actively partnered with the WAHTN Consumer and Community Involvement Program to facilitate a Community Conversation event to bring together young people with a disability, and their parents and carers to discuss and capture feedback around their priorities for research. The information obtained during the event will be used to inform the focus of research for the development of a new research domain, establishing the fourth of the Institute's intersecting research focal areas. The other three domains cover Mental Health, Alcohol and Drugs, Dementia and Ageing. The Institute is forming a specific Disability and Inclusion Domain to focus on this research, and the conversation will inform this work.



WHAT IS THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM?



The Consumer and Community Involvement Program (CCIProgram) supports consumer and community involvement across the Western Australian Health Translation Network (WAHTN) partner organisations.

CCIProgram's **Vision** is to improve lives by ensuring the community's voice is heard and understood in health research

CCIProgram's **Mission** is enabling consumer and community involvement in health research by supporting and connecting community with researchers, partners and policy makers.

In order to achieve CCIProgram's Vision we:

- Are inclusive
- Trust, respect, support and value each other and those we work with
- Work as a team
- Are relevant and sustainable so as to make a difference.

WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method[1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event.[2],[3] Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.



[1] Brown, J., & Isaacs, D. (2005). *The World Café : Shaping our futures through conversations that matter*. Barrett-Koehler

[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, *Topics in Stroke Rehabilitation*, 29:5, 392-400.

[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. *The Journal of Special Education*, 55(3), 131-142.

ABOUT THE COMMUNITY CONVERSATION

The Curtin University enAble Institute and Curtin Involve Team recognises the unique perspective consumers and people with lived experience can contribute regarding their personal health background. In partnership with the CCIP Program, a Community Conversation was planned to gather and collect thoughts and attitudes from young people with a disability, and/or their parents/carers.

The aim of this Community Conversation was to promote discussion of common challenges or concerns shared by people with disabilities, irrespective of diagnosis. The Institute's team wanted to have input on what to focus on as a collective and ensure that their research was relevant and would address what was seen as the most important unmet needs of young people with a disability.

"The best thing about the Community Conversation was providing the space for us to put up all the challenges and issues that are looking for a better solution"



STRUCTURE AND PROCESS

On Wednesday 22 May 2024, a total of 10 young people with a disability (age ~16-25) and/or parents/carers of children/young people (0-25) with disabilities attended the event along with 6 members of the CCIProgram and 3 Curtin University enAble Institute and Curtin Involve team members.

To ensure attendees fully understood the purpose of the Community Conversation, Professor Bronwyn Myers, Director of the Curtin University enAble Institute presented providing an overview on the Institute and the purpose of the research. Deb Langridge, Head CCIProgram provided an overview on the process.



Attendees were then split between 2 tables. Each table had a facilitator from the CCIProgram to help guide the discussion and a scribe from the Institute's team to collect all attendee feedback.

Facilitators posed 3 questions in total to the group; each individual question was allotted 25 minutes for discussion. The comments, feedback and suggestions were all captured by each scribe and are presented in the following pages of this report. Following the questions, the table facilitators summarised the key thoughts and ideas.

These key thoughts and ideas were consolidated by the table facilitators into 12 potential research focus areas. These were transferred on to paper sheets and attendees were then provided with a Dotmocracy activity, whereby they could place 3 dots against the research focus area/s they felt were the most important to them.

PROMOTION

The Curtin University enAble Institute and Curtin Involve team worked closely with the CCIP Program to recruit young people with disabilities, and their parents and carers to hear what their priorities for research are. We shared promotional communications across multiple channels.

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

COMMUNITY CONVERSATION



WE SEEK YOUNG PEOPLE, PARENTS/CARERS OF CHILDREN/YOUNG PEOPLE WITH DISABILITY

Curtin's enAble Institute would like to speak with young people with disabilities, and their parents and carers, and hear what their priorities for research are.

The enAble Institute is forming a specific Domain to focus on this research, and this Community Conversation will inform the work.

A \$70 honorarium is offered to attendees and light refreshments will be provided.

Register your interest

WHEN: Wednesday 22nd May 2024
TIME: 10am to 12:30pm
WHERE: Bentley Technology Park
2 Brodie-Hall Dr, Bentley



<https://bit.ly/3UDBgAV>



THE COMMUNITY CONVERSATION TEAM



Deb Langridge - Head, CCIP Program

Lead Facilitator

Deb has worked in the public health and prevention space at all levels of government – Federal, State and Local – and not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of community including access and inclusion, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, children and young people, mental health, health and community services. Deb has been the Chair of Advisory Groups in both NSW and WA. She has always worked connecting community, government, and community with a well-being focus, and was a representative on WA Sustainable Health Review with this in mind.

Deb's role leading the Consumer and Community Involvement Program as a platform of the Western Australia Health Translation Network is to connect researchers in WA Universities, Medical Research Institutes, Government, and Health Service Providers with people with lived experience to support and encourage best practice research. Deb is passionate about ensuring research can impact policy, practice and wellbeing of communities and enjoys bringing people together to make a difference.



Caroline Jones, Matt Hands, Ingrid Laing and Kerry Mace - CCIP Program

Table Facilitators

Thankyou to the CCIP Program facilitators for their assistance in facilitating the conversation with the attending community members.

THE COMMUNITY CONVERSATION TEAM



Professor Bronwyn Myers **Director of the Curtin enAble Institute**

Professor Bronwyn Myers is the Director of the Curtin enAble Institute, an interdisciplinary Research Institute focused on mental health, alcohol and other drug use, disability, dementia, and ageing. Previously, she was the Deputy Director of the South African Medical Research Council's Mental Health, Alcohol, Substance Use, and Tobacco Research Unit where she still holds an honorary appointment. She also has an honorary appointment at the University of Cape Town's Department of Psychiatry and Mental Health. Prof. Myers conducts clinical research focused on the development, testing, and implementation of psychological and health system interventions to improve access to, outcomes, and quality of care for people with substance use and co-occurring mental and physical disorders. Her work has a strong lived experience and workforce development focus and emphasizes principles of co-design, mutual capacity building, and equity.

Thankyou to the Curtin University enAble Institute scribes, Chloe Buchanan and Danielle Anaru for their assistance in scribing the conversation with the attending community members.

AGENDA

enAble Institute 'All Abilities' Community Conversation
 Wednesday 22nd May 2024 – 10am to 12:30pm
 Bentley Technology Park

9.30am	Registration & morning tea	All
10.00am	Welcome <ul style="list-style-type: none"> • Acknowledgement of Country • Welcome to the workshop • Introductions 	Deb Langridge
10.10am	Presentation & questions	Prof. Bronwyn Myers
10.20am	Process of the day	Deb Langridge
10.25am	Question 1: What are the biggest challenges you (your child/young person you are for) face on a daily basis? (25 mins)	All
10.50am	Question 2: What are some of the things that help you (your child/young person you care for) on a daily basis? (25 mins)	All
11.15am	Question 3: What do you think researchers in the disability sector should focus on? (25 mins)	All
11.40am	Table feedback	All
12.00pm	Next Steps and Opportunities for Involvement	Deb, Bronwyn and Briony
12.10pm	Dotmocracy	All
12.25pm	Evaluation, honorarium and thanks	All
12.30pm	Close	

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 1: What are the biggest challenges you (your child/young person you care for) face on a daily basis?

Question Prompts:

- What do you/your child/the young person you care for need help with?
- What services are lacking?
- What are some misconceptions about your disability/your child's disability/the disability of the young person you care for?

Participants described their experiences and daily challenges with most participants describing being in caring roles for a young person with a disability and many identifying as themselves having a disability.

A range of common themes arose from these discussions including;

Lack of awareness, information and access:

- Many participants spoke of one of the biggest challenges being a lack of awareness and information leading to a lack of access. Participants spoke of "navigating the hospital system" and "battling education support" along with needing an awareness of what services are available. This was described as "need help but don't know where to go"
- This lack of awareness and information extended beyond carers and was described as a lack of training across educators, schools, doctors and allied health). Service providers were describe as not knowing who to reach out to, did not direct to other services after diagnosis and "don't know about each other".

Relationships:

- Challenges described by participants spoke of the impacts on mental health and on impacts within relationships and families. Consumers spoke of carers being emotionally strained and that this feeds into couple time for parents. Some consumers spoke to the topic of having low self-esteem while others spoke of experiencing an abusive relationship.
- Parenting relationships featured strongly with the desire for support in trying to upskill the person (child) they care for. This consumer spoke of "no mentors to help you through it as a parent/carer".

Education:

- School system and finding and accessing appropriate educational services, specific to need. Consumers described current system does not match needs "We don't fit with what's available – they're falling through the cracks". Consumers described this as "wasted youth" with the school environment "not made for our kids" and by the time services were available it's too late.
- One participant spoke of challenges within a university setting with an inability to complete a required placement due to a lack of supports available.
- Broadly a lack of knowledge/ education of the public, services and health professionals was seen as having a negative impact

QUESTION 1 (continued):

What are the biggest challenges you (your child/ young person you care for) face on a daily basis?

Invisible disability:

- Many consumers identified a challenge within invisible disability and how these types of disabilities are not seen and consequently not given sufficient attention.
- Stigma was raised as a prevalent concern with misconceptions shared about assumptions around intelligence, bullying and name calling described. Misconceptions about invisible disabilities was described as "They don't look disabled".
- Participants spoke of a need to educate around the definition of disabilities within the public mind and one consumer talked about education support for a parent refusing to believe the diagnosis.

Delayed diagnosis:

- Participants spoke of misdiagnosis and delayed diagnosis causing restrictions on access, causing difficulty and a lack of support.
- Lack of services, delays and wait times were a prevalent theme with the referral waitlist being described as "years long" and impacting the ability to access appropriate medications/ treatments for prolonged periods. These delays were described as having the impact "by the time they are available, it's too late or near the end of school age".
- A topic aligned to delayed diagnosis was that of gender difference in diagnosis age due to female presentation of autism. This was discussed in relation to the impact of the issue due to NDIS funding cutoffs relating to diagnosis by 7 years of age.

Socialisation:

- A challenge lay with children having a lack of social connections and having difficulty in finding these social connections.
- A lack of opportunities to socialise and create friendships was described as impacting social and emotional development
- Lack of social connection opportunities exacerbated for older teens with limited opportunities catering to this group.

Pain management:

- A few participants made note of the management of pain, discomfort, tiredness, specific symptoms of their conditions and the implications from pain management medication.

Cultural Diversity:

- Lack of support due to not having permanent residency. Not having permanent residency impacts access to NDIS, employment, and resources.
- Multicultural services due to not being able to express their situation and feelings in English.

COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 2: What are some of the things that help you (your child/ young person you care for) on a daily basis?

Question Prompts:

- Who are the people that help?
- Which services help the most?
- What can we learn from your disability/your child's disability/the disability of the young person you care for?

Participants responded with many common themes emerging from responses to this question:

Therapeutic and Personal Support Services:

Participants cited therapeutic interventions (psychology, occupational therapy, speech therapy, physiotherapy) and personal support services (support workers helping with transportation, house cleaning and home-schooling) as helping.

Organisations:

Participants described a range of community support services as helping including support services targeting women such as support groups and domestic violence services, parents' groups, health clinics and local government provided services such as youth centre, library, and school holiday program.

Several specific organisations were named as having helped including;

- Perth Childrens Hospital team
- Kiind Organisation- parents with lived experience volunteering in services attached to PCH, supporting the capture of people's stories, and looking at service gaps for future research as well as sending out information about opportunities
- Arthritis and Osteo WA
- NDIS counselling school leaver's program (waitlist)
- Carer's WA Carer's Gateway Phone Counselling (3-month waitlist)
- Headspace

Similar lived experience:

A common theme among participants was that help was derived from contact with those who had a similar lived experience. Participants described the sharing of experiences, challenges, and resources through support groups, face to face peer groups, online chatgroups and homeschool networks. Facebook chatgroups were described as used to ask things like "Which school would you recommend?" providing immediate answers. Some participants stated that sharing challenges with other people who face similar situations can be helpful and many described sharing resources with others who have lived experience.

QUESTION 2 (continued):

What are some of the things that help you (your child/ young person you care for) on a daily basis?

Self-care:

Activities that focussed on maintaining mental health was a common theme with participants describing the need for self-care as “no one is caring for the carers”. Participants talked about “what makes me happy?” and “time to focus on me” and taking time to focus on themselves separate to their caring responsibilities. Activities included pottery/ art, as well as seeking (free) counselling and for some participants self-determined advocacy (however appeared to reduce carer’s own capacity /mental health)

Social:

Social networks were raised as ‘things that helped’ with participants finding this connection through carers/ friends, family, and homeschool network. One participant expressed that friend’s “treat her normal” while another participant described sharing social stories as helpful.

Participants raised other aspects for ‘things that helped’ including;

- Awareness at all levels (public, professional, teachers) from lived experiences, making accessible resources and having people with disabilities voices be heard
- People need to come together to collaborate (professionals and people with lived experience)
- Workplace flexibility
- Volunteers/ volunteering experience
- Sticking to routine for children with autism
- Carer’s pension



COMMUNITY CONVERSATION FINDINGS

Attendee Insights

QUESTION 3: What do you think researchers in the disability sector should focus on?

Question Prompts:

- What is unknown about your disability/your child's disability/the disability of the young person you care for?
- Are there any/enough treatment options?
- Are there any/enough services and support available?

Numerous responses were collected from participants regarding this query with participants putting forward the following potential research themes;

Relationships:

- Impact on relationship - family support
- Parenting techniques - for those with children or are carers to those with a condition.
- Parenting children with chronic health conditions/disabilities - dissemination of knowledge and ways to parent
 - managing the stress of parenting a child with disabilities; many relationships end in divorce
 - "you could just burnout trying to find stuff"
 - "there's no manual"
 - "knowing what does work and what doesn't"
- How to support mothers/carers as a male partner □ Fathers deny diagnosis more than the mothers (links back to invisible disability)
- Socialisation techniques - helping those with disabilities to socialise.
- Recognition of different needs among people of different ages

Pathways/ 'hub of support':

- Improving parents' accessibility to knowledge about parenting children with disabilities, services available/where to get help
- How to integrate support so they do not have to go to many different places to find the adequate resources

Culture:

- CALD groups being included and having a voice on how to parent children with disabilities
- Focus on how culture can impact the person with the disabilities (in traditional Chinese culture they see a child with a disability as worthless and offer them minimal resources)
- Cultural conflict

Gender:

- Gender differences in autism, particularly;
 - girls getting later diagnoses due to differences in presentation/ masking impacting funding age cutoffs at 7 years
 - getting help for girls earlier, recognising signs/symptoms earlier

QUESTION 3 (continued):

What do you think researchers in the disability sector should focus on?

Communications:

- effective communication to and between service providers, carers, those with disabilities.
- service providers don't know who to reach out to and services don't know about each other
- Communication when transitioning between systems/hospitals

Education in school system:

- Education system
- improving schooling system by providing help to better fit young people with a disability who are "falling through the cracks"
- old-fashioned approach in Australia
- wanting education to be similar to Finland's system where there is no diagnosis required as kids needs are met or dealt with on a 'as needed' basis
- teachers not having enough time – too big a workload "teachers to teach, not do testing"
- classrooms that are more suited to children of all abilities allowing for different skills, reflecting that not all kids are academically driven or able to sit at a desk all day
- Education for men with mental health diagnoses and/or children with diagnoses

Pain management:

- chronic pain
- managing it from a different perspective
- implications from medication

Costs:

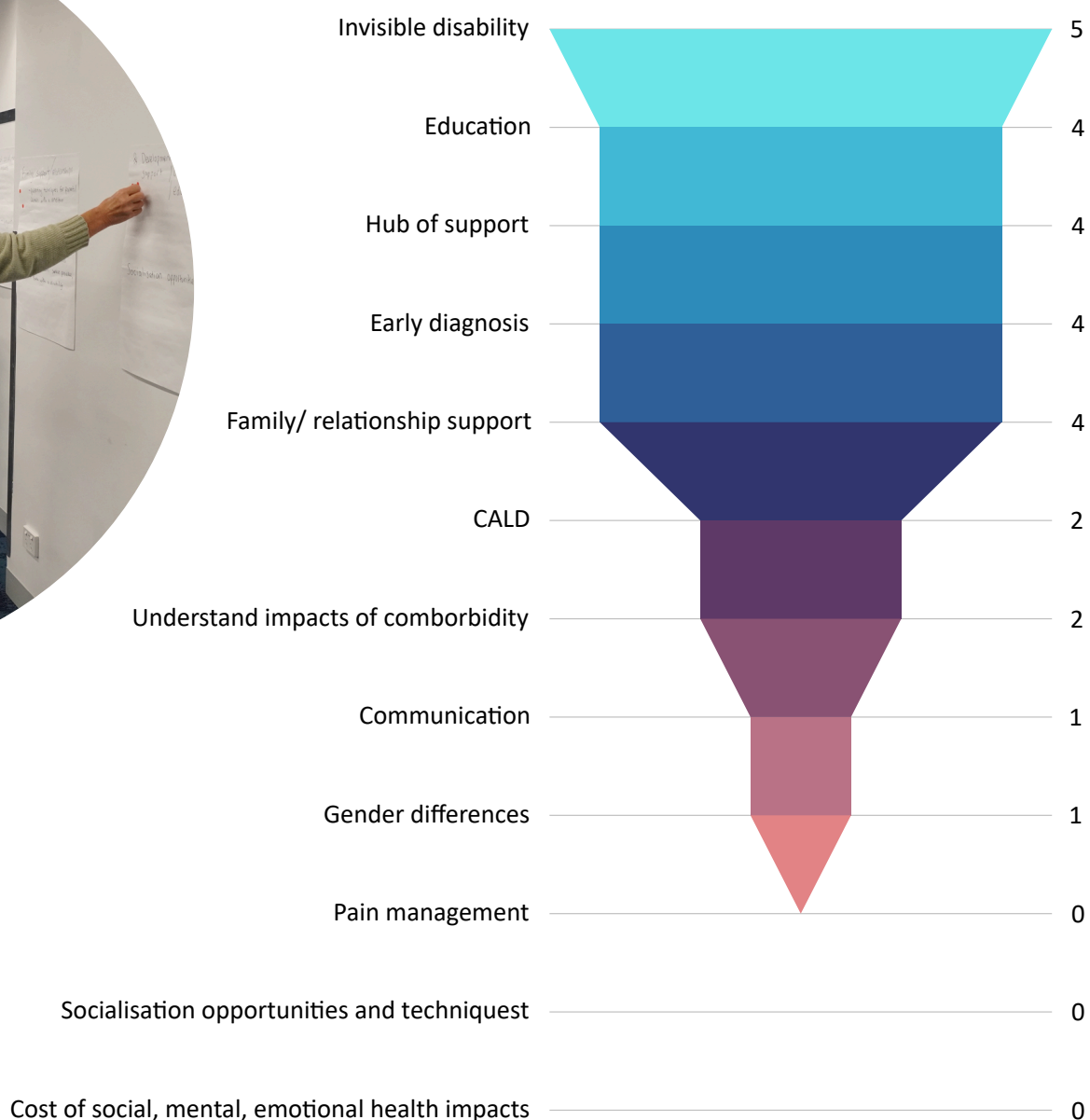
What are the emotional costs, social costs, and mental health costs of living with disabilities? (researching comorbidities, and various diagnoses)

Other research areas suggested included;

- Wait/cost of diagnosis
- Community forums children/kids with disabilities to be a voice for their needs
- Gaps in services
- young people mentoring young people with disabilities
- Acceptance
- Identity crisis -> low self esteem

DOTMOCRACY RANKING OF KEY THEMES OF THE COMMUNITY CONVERSATION

Following discussion of the three questions, table facilitators identified the key themes that has arisen during the discussions and presented these 12 consolidated themes on paper sheets on the wall. Attendees were then provided with 3 dots and asked them to place their dots against the research focus area/s they felt were the most important to them. This table provides the results from these votes.



EVENT SUMMARY

Evaluation and feedback from attendees were collected through the CCI Program following the closing of the Community Conversation (see Appendix 1). The consensus from all who attended was that the Community Conversation was extremely informative, interactive, and engaging. Attendees were enthusiastic around their involvement with this particular event and commented that they felt their contributions were valued and appreciated. Overall, the event was extremely successful and will allow for the Institute's team to provide informed consumer and community member feedback for further grant opportunities and research priorities.

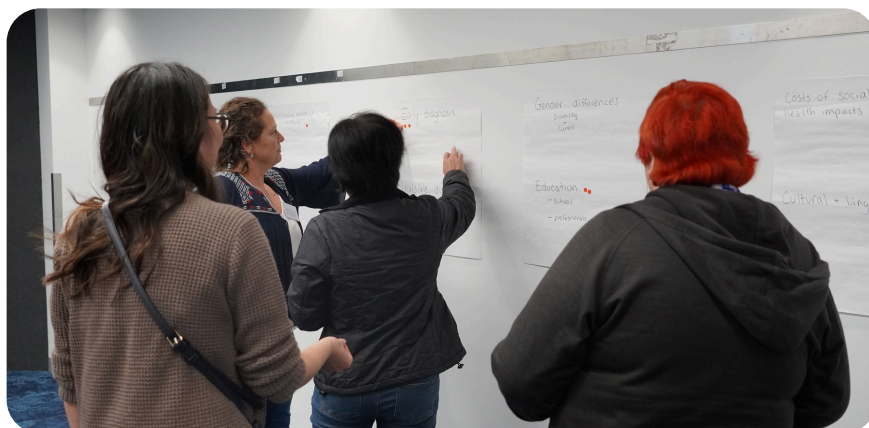


WHAT'S NEXT?

The Institute's team found the information that came out of the Community Conversation very informative, and will be using details and views provided in the formation of research priorities for the new 'Disability and Inclusion' domain.

The Institute's team will use the outcomes of the Community Conversation to develop new research projects that address key challenges faced by young people with a disability and/ or their parents/ carers.

We would like to continue to learn from those with lived experience and intend for this to be the first of many conversations. This will include follow up conversations that ensure people unable to attend due to location, caring responsibilities or communication needs are able to be involved through other opportunities including online. The research focus will also broaden to span whole of life with additional conversations focussed on other life stages.



APPENDIX 1

enAble Institute 'All Abilities' Community Conversation Evaluation Summary

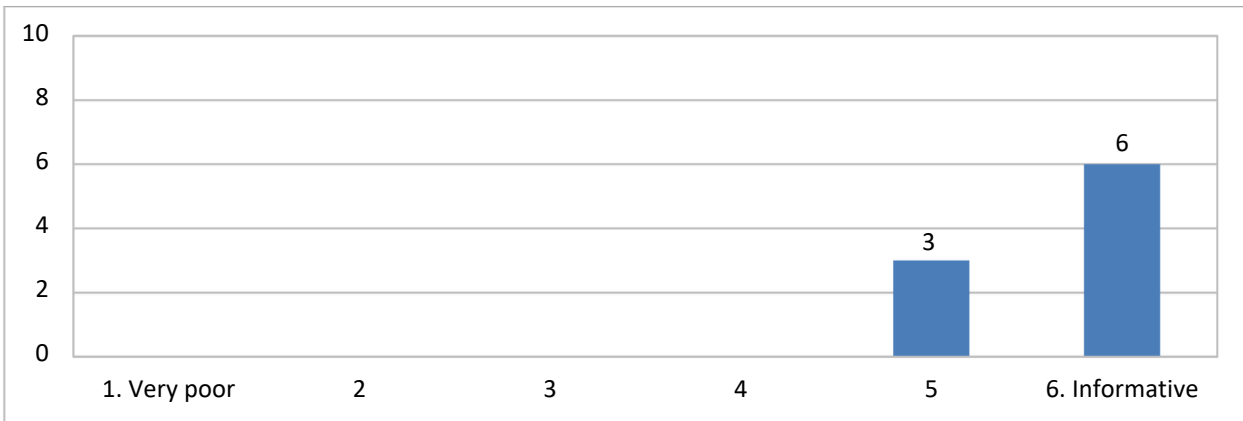
9 Forms completed / 10 attendees

Please tick the responses which best match your view:

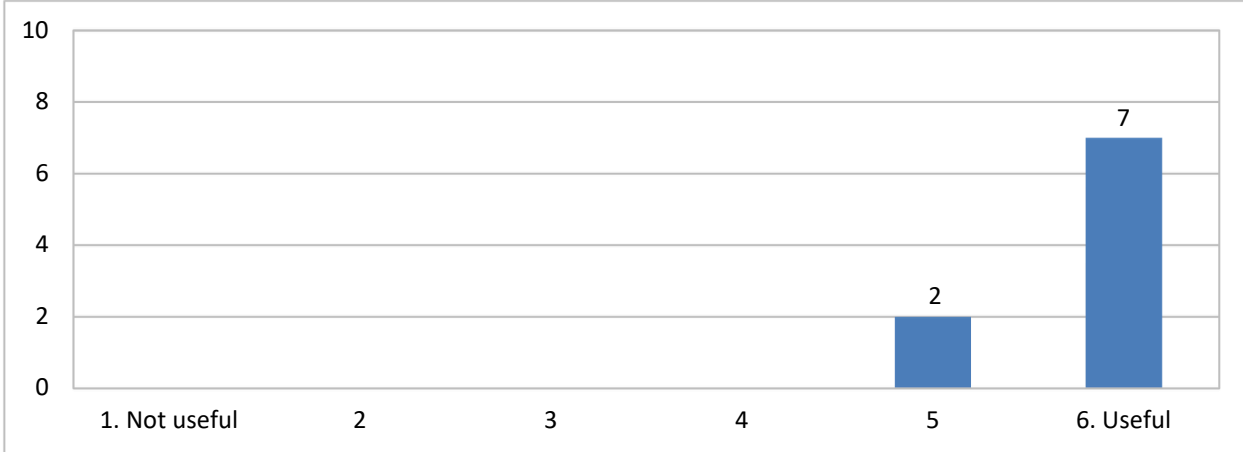
1. The Community Conversation was:



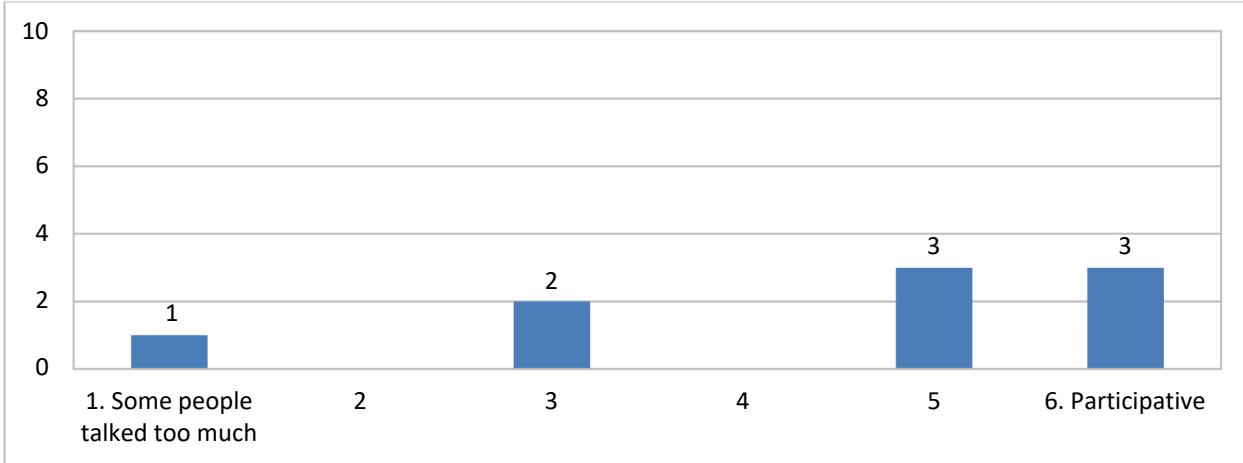
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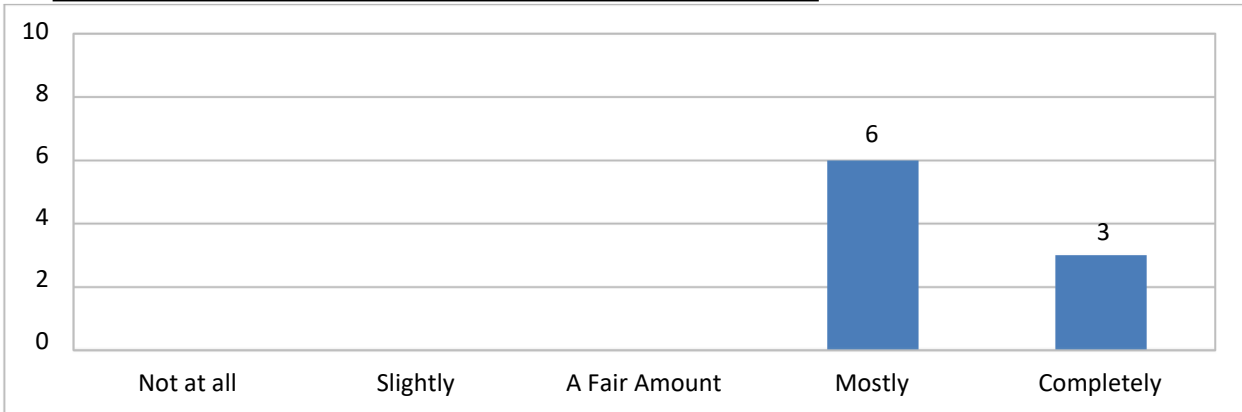
1.2 *Useful*



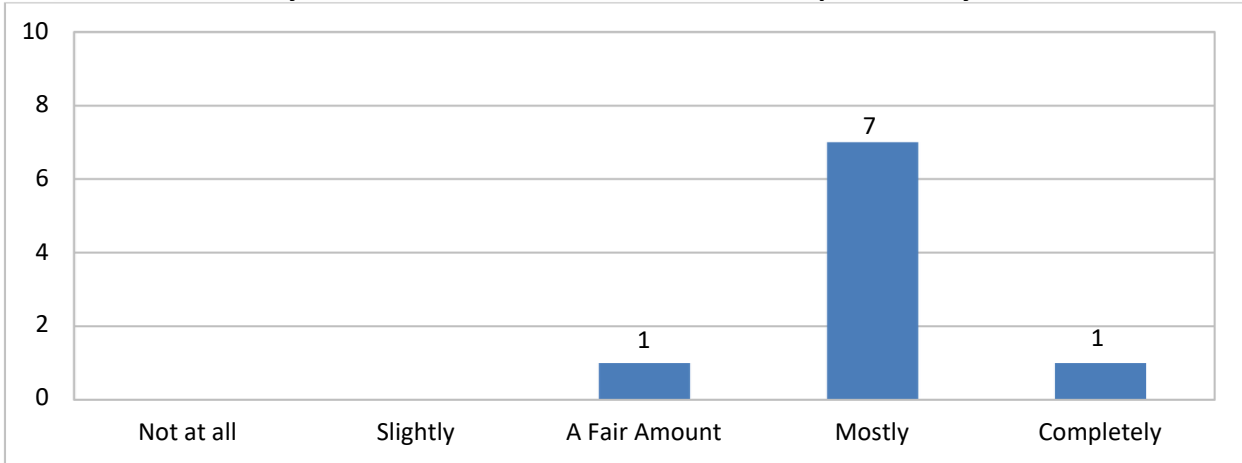
1.3 *Participative*



2. **Did the community conversation meet your expectations?**



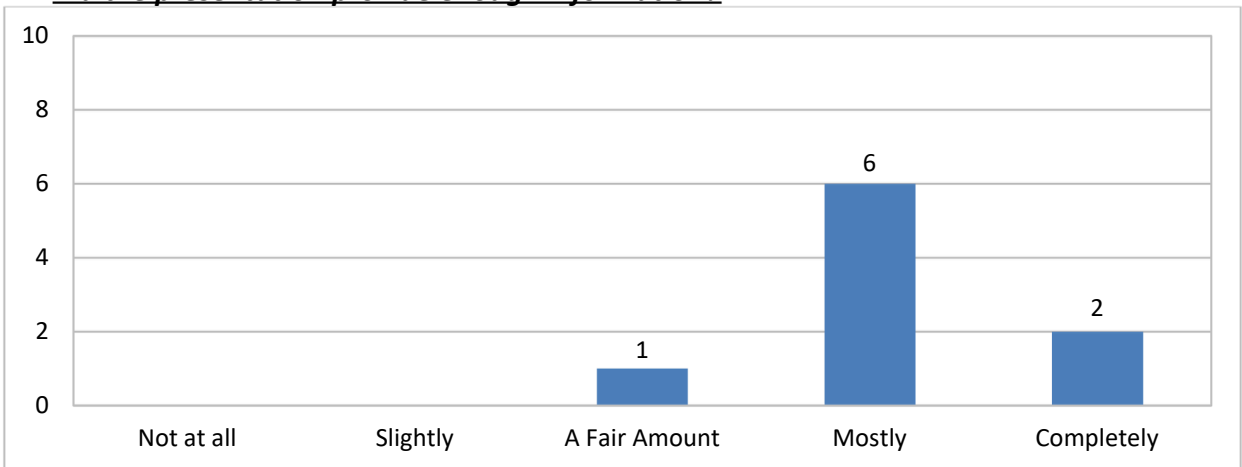
3. **Did the community conversation cover areas that were important to you?**



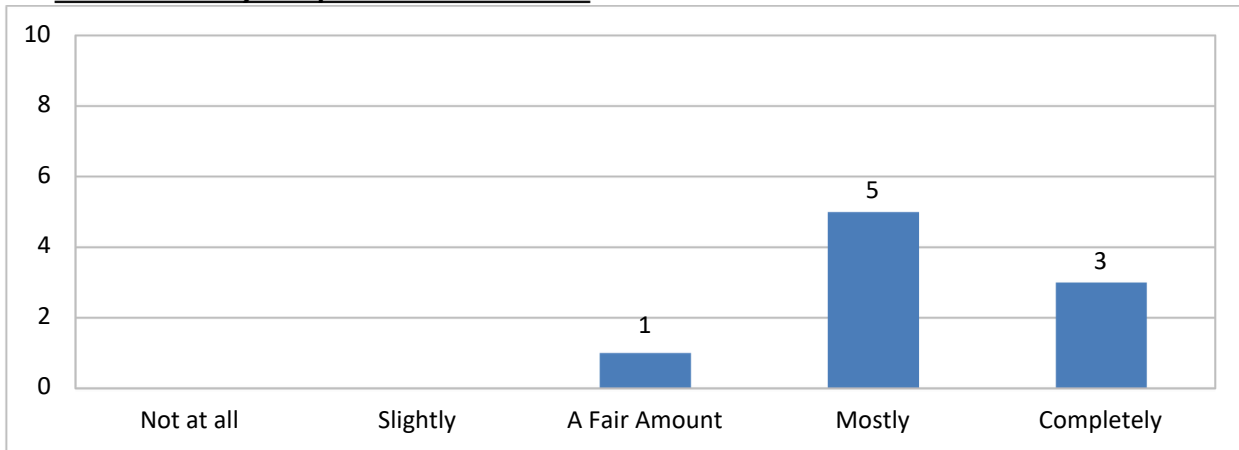
If "not at all" please specify what additional information could have been included:

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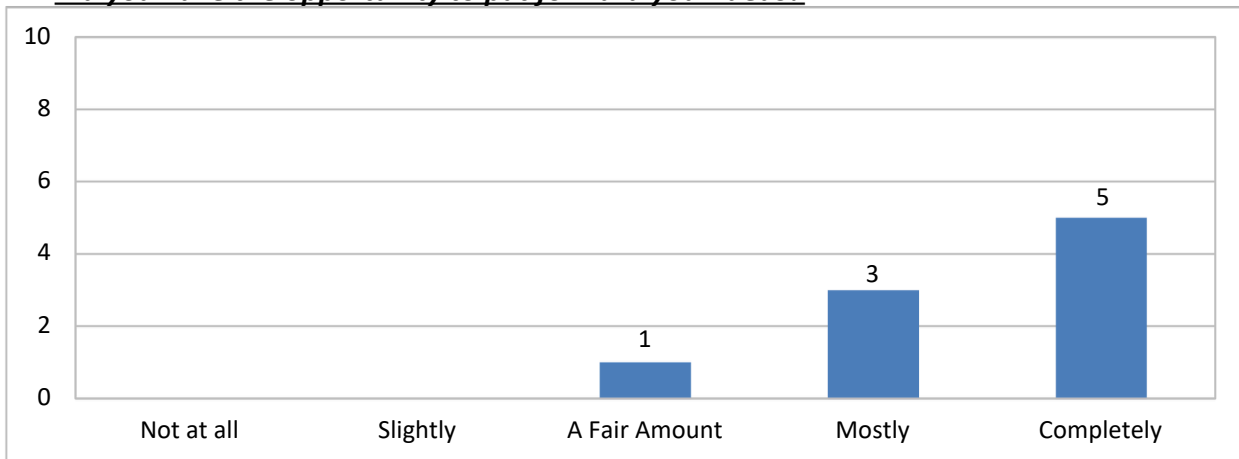
4. **Did the presentation provide enough information?**



5. **Did well were your questions answered?**



6. **Did you have the opportunity to put forward your ideas?**



7. **Is there anything else you would like to add?**

- Would be great to have a 'handbook' given to parents on where to get help
- Perhaps some crossover re: interagency doing similar work e.g. PHC/Kiind – if not already?
- Being mindful that some people are at different stages of their disability/support journey (self-reflection)
- Care for kids through inclusive education and care for parents with information and support
- More conversations in future
- Vulnerability

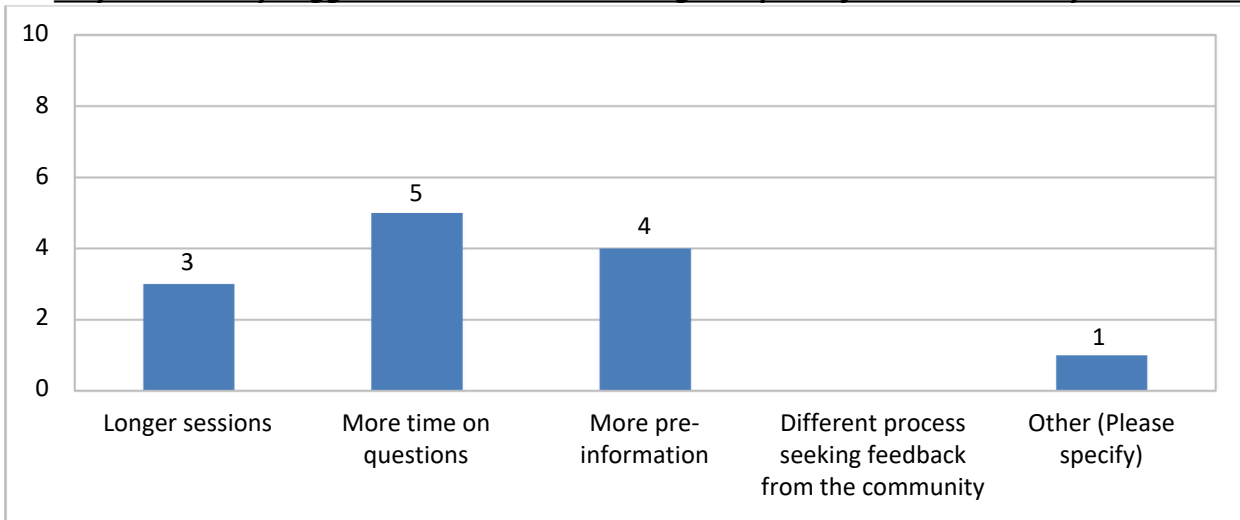
8. **The best thing about the community conversation was:**

- Great friendly atmosphere where you feel listened to and understood
- Learning from others
- Hearing the shared lived experiences
- Having people interested in my needs as a carer
- There are more than one of us
- Includes all perspectives
- Providing the space and table for us to put up all the challenges and issues that are looking for a better solution
- Meet people with similar experiences

9. ***The worst thing about the community conversation was:***

- Not having enough time to learn from others who are going through/have gone through the same issues you are dealing with
- Not enough time

10. ***Do you have any suggestions about how we might improve future Community Conversations?***



Other (Please specify):

- Young people advocating for themselves/CALD

WANT TO KNOW MORE?

PHONE: (08) 6151 1071

E-MAIL: ADMIN@CCIPROGRAM.ORG

WEBSITE: WWW.CCIPROGRAM.ORG

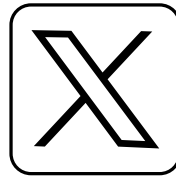
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