

Youth Engagement in Research Partnerships: Exploring Training Needs of Youth with Neurodevelopmental Disabilities

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McMaster Child
Health Research Day
2022

BACKGROUND

Patient-oriented research (POR) is a “continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes” according to the Canadian Institutes of Health Research.¹

What are the gaps?

Lack of tailored POR training available for youth with **neurodevelopmental disabilities (NDD)** ages 18-25

Needs and training opportunities expressed by youth with NDD at CP-NET Stakeholder Meeting

Formation of CanChild's Youth Engagement in Research Team in August of 2020



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Knowledge Translator



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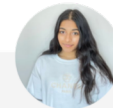
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1. Government of Canada, 2019. *Strategy for Patient-Oriented Research - Patient Engagement Framework*. [online] Canadian Institute of Health Research. Available at: <<https://cihr-irsc.gc.ca/e/48413.html>>

RESEARCH QUESTIONS

1) What are the training needs for adolescents and young adults with neurodevelopmental disabilities to enhance their knowledge, confidence, and skills, as research partners?

2) What are the benefits and challenges of engaging in an integrated knowledge translation (iKT) research approach?



METHODS

Phase I: Individual Interviews



Youth with NDD (age 18-25) are consulted about barriers and needs in POR.

Phase II: Virtual Symposium September 15 & 25, 2021

Youth and researchers from various NDD networks were invited to further discuss training needs, brainstorm delivery methods, and prioritize training topics.



Phase III: Training Material Development

Co-development of training opportunities for youth and researchers.

Data from interview, virtual symposium, and the literature will inform the training material content.

Qualitative Content Analysis

- Two members independently analyze each transcript from interviews via Dedoose.
- Interview and virtual symposium data compared.
- Generated codes were organized into a codebook.

Knowledge Translation (Ongoing)

METHODS

Integrated Knowledge Translation Approach (iKT)

- **Co-investigators:** four youth with lived experience, one parent with lived experience, and five researchers
- **Communication methods:** monthly full team meetings, email correspondence, individual check ins between student investigator and partners before each study phase
- **Tools:** Involvement Matrix (track tasks and level of contribution) during individual check ins; Public and Patient Engagement Evaluation Tool questionnaire administered to partners at the end of each phase (reflect on the iKT process)^{2,3}

Patient partners' contributions throughout the research process

Preparation

- Co-designed protocol
- Shaped focus group and interview questions
- Filmed recruitment videos
- Provided feedback on ethics and grant application

Execution

- Recruited participants
- Conducted focus groups and interviews
- Co-hosted and facilitated the virtual symposium
- Collaboratively analyzed qualitative data

Knowledge Translation

- Co-developed prototypes of training opportunities (video and infographic)
- Co-presented findings at research conferences
- Manuscript preparation

2. Smits DW, Van Meeteren K, Klem M, Alsem M, Ketelaar M. Designing a tool to support patient and public involvement in research projects: the Involvement Matrix. Research involvement and engagement. 2020;6(1):1-7.

3. Public & Patient Engagement | PPE Evaluation Tool [Internet]. healthsci.mcmaster.ca. 2018. Available from: <https://healthsci.mcmaster.ca/ppe/our-products/public-patient-engagement-evaluation-tool>

PRELIMINARY RESULTS

Phase I: Interview

What are the training needs for adolescents and young adults with neurodevelopmental disabilities to enhance their knowledge, confidence, and skills, as research partners?

Table 1. Interview Demographic

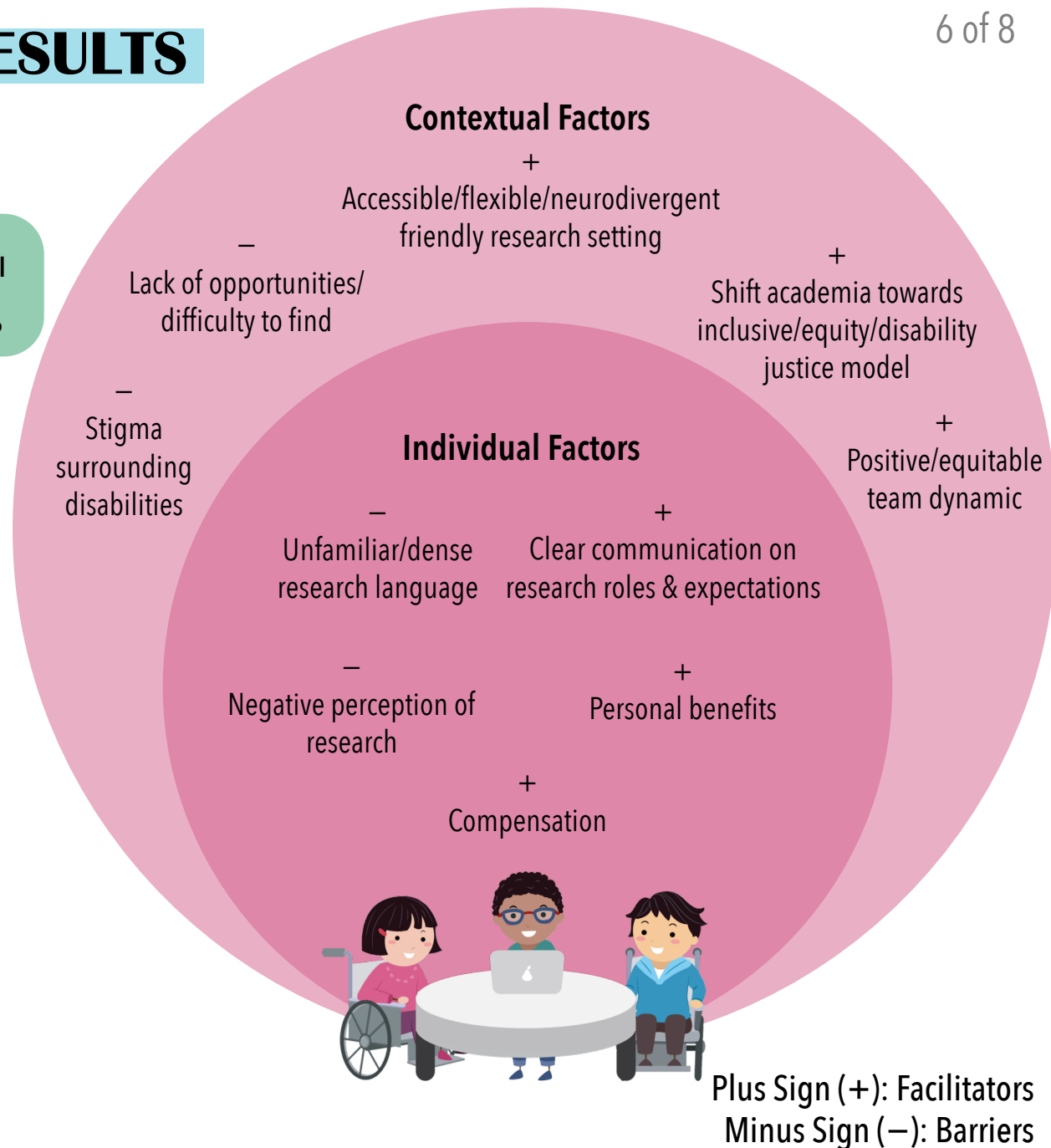
| | n | % |
|-------------------|---|------|
| Youth (age 18-25) | 7 | 100% |
| ASD | 1 | 25% |
| CP | 2 | 25% |
| ADHD | 3 | 38% |
| ASD and ADHD | 1 | 13% |
| Gender | | |
| Male | 2 | 25% |
| Female | 3 | 38% |
| Other | 2 | 25% |

Acronyms

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

CP: Cerebral Palsy



PRELIMINARY RESULTS

Phase II: Virtual Symposium

What are the training needs for adolescents and young adults with neurodevelopmental disabilities to enhance their knowledge, confidence, and skills, as research partners?

Table 2. Virtual Symposium Demographic

| | n | % |
|-------------------|----|------|
| Total Participant | 17 | 100% |
| Youth (age 18-25) | 10 | 59% |
| ASD | 1 | 6% |
| CP | 4 | 24% |
| ADHD | 3 | 18% |
| ASD and ADHD | 1 | 6% |
| CP and ASD | 1 | 6% |
| Researchers | 7 | 41% |
| Gender | | |
| Male | 5 | 29% |
| Female | 11 | 65% |
| Other | 1 | 6% |

Prioritized Training Topics

1. Communication training between youth and researchers
2. Research roles and responsibility
3. Finding research partnership opportunities

Potential Training Formats

- Mentorship (personal check-ins)
- Online interactive modules
- Integrate quizzes, activities, and reflections
- Simulations (e.g., scenarios + solutions)
- Videos with a person speaking 'to you'
- Whiteboard animations with narrator voiceover

DISSEMINATION

8 of 8

Presentations

2021 Children's Healthcare Canada Conference

2021 CP-NET Science and Family Day

Youth Engagement in Research
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Preliminary Findings:

Prioritized Training Topics

- Enhance communication between researchers and youth
- Better understanding of the research process and roles
- Knowledge of where to find partnership opportunities

Table 1. Preliminary codes from focus group and interview content analysis.

| CODE | DESCRIPTION | EXAMPLES |
|-------------------------------|---|--|
| Barriers | Factors that make engaging in research challenging between youth and researchers. | <ul style="list-style-type: none"> Lack of research opportunities Language and communication barriers Physical disabilities Health disparities |
| Facilitators | Factors that make engaging in research easier between youth and researchers. | <ul style="list-style-type: none"> Clear feedback and safe space environment Online research Collaboration Community Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement |
| Delivery Methods for Training | How to deliver training to researchers, youth, and researchers. | <ul style="list-style-type: none"> Online research Collaboration Community Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement |
| Benefits | Benefits perceived by the researchers and youth. | <ul style="list-style-type: none"> Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement Researcher's role in youth engagement |

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Visit our study website: www.youthengagementinresearch.ca



Youth Engagement in Research Partnerships
Exploring Training Needs of Youth with Neurodevelopmental Disabilities

Presented by Samantha Dong & Amanda St. Dennis on behalf of the CanChild Youth Engagement in Research Team

CanChild Youth Engagement in Research Team:

- Jan Willem Gorter, PhD, Professor, University of Alberta
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- David Kirby, PhD, Postdoctoral Fellow, CanChild
- David Soper, PhD, Postdoctoral Fellow, CanChild

Logos: CanChild, McMaster University, CHILD-BRIGHT Network, Mitacs, CP-NET Childhood Cerebral Palsy Discovery Network

NEXT STEPS

1. Co-develop a training material prototype (e.g., videos and infographics) – created *by* youth and researchers *for* youth and researchers.
2. Complete the manuscript, which will report on the results from the interviews and virtual symposium.



Potential Impact

Training opportunities could bring more lived experiences onto research teams, ensuring more meaningful and relevant research that benefit patient stakeholders.

INSTRUCTIONS

DELETE this slide prior to submitting your presentation – it is intended for guidance only

Slide structure & submission

- The goal is to highlight the significance of your work by presenting complex information in an engaging, accessible, and compelling way.
- Your presentation should contain 8 slides: 1 title slide + 7 content slides
- **The 7 content slides should address the following (select headers applicable to your research): background, research question, methods, results, discussion, knowledge translation/next steps/implications of the work.**
- You will need to convert your final 8 slides (1 title slide + 7 content slides) from Powerpoint to PDF (File>Save As Adobe PDF). Use the **last name of the principal applicant & Session # as the file name (e.g. Smith A1).**
- Once registrations have been processed, you will receive a link to upload your slides as a single PDF file (1 title slide + 7 content slides). Use the last name of the principal applicant & Session # assigned as the file name (e.g. Smith A1).
- The deadline for submission is **March 23, 2022.**

What to expect

- Each presenter will have 5 minutes to deliver an oral presentation of their work. An additional 3 minutes will be allotted for questions from the audience.
- Presentation sessions will be facilitated by a faculty member.
- Slides will be managed centrally during the session. Your session's administrative lead will display and advance your slides on your cue (*'next slide, please'*). Please also have your slide deck available/open on your computer in the event of unforeseen technical issues.