

Parents Participating in Research Facebook Group

Engagement

You are receiving this survey as a member of the Facebook Group "Parents Participating in Research". We would like to know how this group is doing and how we could move forward. It should take you about 10 minutes. The results will be shared with all participants and serve as a baseline for future surveys. Thank you for taking the time to share your ideas!

You might participate in this group in different roles, depending on the topic that is being discussed (parent of a child with disability, person with a disability, researcher, friend of people with disability etc.). When you first heard about this group, what was the main reason that made you decide to join?

- Due to my personal experience with childhood onset disability
- Due to my research interests in childhood onset disability

Parents Participating in Research Facebook Group

Research

How confident/knowledgeable did you feel in understanding research before joining this group?

not at all

very
confident/knowledgeable

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How confident/knowledgeable do you feel in understanding research now?

not at all

very
confident/knowledgeable



A horizontal Likert scale consisting of 10 radio buttons arranged in a row on a light gray background. The scale is positioned between the labels 'not at all' on the left and 'very confident/knowledgeable' on the right.

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What best describes your use of this Facebook group?

	never	once a month or less	every other week	weekly	almost daily
I read the posts/comments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I like posts/comments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I comment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I post	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you responded "once a month" or "never" please tell us what might increase the frequency of your actions?

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Experience

Please tell us what your expectations were when you joined this group?

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Do you feel this group is a safe place to discuss health related or research related topics?

- Yes, I feel safe to post sensitive/personal information
- I regulate what I post
- I do not post, only read

Please explain

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Do you feel supported by the other members in this group?

lack of support

fully supported



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How would you describe the activities of the moderators of the group?

	not at all	too little	just the right amount	too much
Engaging members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Posting new topics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Refocusing discussions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Summarizing discussions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any comments or suggestions? Please let us know!

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Tell us a bit about why you are using this Facebook group! Please check all that apply and feel free to comment!

- to find information, e.g. search or ask a question
- to share ideas and solicit feedback
- to raise awareness about issues related to disability
- to connect with like minded people
- to get/give emotional support
- to have an impact on childhood disability research

Comments

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Would you recommend this group to other parents, friends or colleagues?

Yes

No

Comments

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As a result of joining this group what have you learned?

- ideas/strategies for advocating for my child at school
- ideas/strategies for advocating for my child with family and friends
- ideas/strategies for advocating for my child with healthcare professionals
- ideas/strategies for myself as a parent of a child with disability
- ideas/strategies for myself as a person with disabilities
- better understanding of research or the research process
- new ideas for future research
- broadened my perspective on the experiences of families

Comments

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As a result of joining this group, have you changed your behaviour or attitude in any way in relation to:

- your child/children?
- your family?
- your friends?
- your patients?
- people with disabilities?
- healthcare professionals?
- research?
- other
- no changes

Please tell us one thing that you have changed as a result of participating in this group?

The Future

If you could change one thing about this group, what would it be?