ORIGINAL RESEARCH

Inclusive Community Aquatics Programming for Children with Developmental Challenges: A Community Participatory Action Research

1. Minnie Teng, BSc. MScOT. Aquafit for All Association, University of British Columbia, Faculty of Medicine
2. Kathy Xie, BSc. University of British Columbia, Faculty of Medicine
3. Julie Engleson, Parent of child with developmental challenges
4. Kanachi Angadi, Parent of child with developmental challenges
5. Anita Wong, BA. Aquafit for All Association
6. Michael Lee, MBA, PDOT, University of British Columbia, Faculty of Medicine, Department of Occupational Science & Occupational Therapy
7. Tal Jarus, MA(OT), PhD (OT). University of British Columbia, Faculty of Medicine, Department of Occupational Science & Occupational Therapy

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ABSTRACT:

Background: Children who are neurodiverse have traditionally been segregated from their peers in community-based programs, despite evidence of health benefits of inclusive education.

Objectives: This community-initiated project aims to explore barriers and facilitators to inclusive aquatics programming for children with developmental and/or mental health challenges.

Methods: Using a participatory-action research methodology, semi-structured interviews and focus groups were conducted with 14 participants from various stakeholder groups, including parents of children who are neurodiverse, helping professionals, and community programmers.

Results: Participants described unique definitions of inclusion, from integration with neurotypical peers, to individualized goal-setting and achievement. Major facilitators include adequate resources, flexibility around accommodations, and motivated staff. Major barriers include social stigma, financial limitations, and lack of communication between caregivers and service providers.

Conclusions: Participants felt strongly about the need to improve inclusion practices within aquatics – and other community-based – programs. Increased collaboration between families, community programmers, and helping professionals can foster better inclusion and outcomes for children who are neurodiverse. By incorporating various perspectives into the design of future programs, program administrators can ensure more equitable access such that all children are able to participate.

KEYWORDS: Leisure Activities, Physical Fitness, Community-Based Participatory Research, Community health partnerships, Community health research, Health promotion, Congenital, Hereditary, and Neonatal Diseases and Abnormalities, Health Services Accessibility, Access, and Evaluation, Community Health Services, Family Health, Children, Neurodiversity, Aquatics

Introduction

Currently, in the aquatic industry, the go-to model of service delivery for children with disabilities has been segregation: where children with additional needs are grouped into adapted, often one-on-one programs separated from peers [1]. However, studies in education have repeatedly shown that inclusion, where children with additional needs are placed in the same environment as typically developing peers, improves their childhood experience and life trajectory [2,3]. In light of evidence around the therapeutic potential of aquatics for diverse children, it is important to investigate how these programs may be best delivered to optimize long term health outcomes [4,5]

The inclusive education model has been shown to improve biopsychosocial outcomes for children with diverse needs[5,6]. Despite the benefits of inclusive education, an extensive literature search across three major search engines (PubMed, CINAL, Medline) revealed that studies on facilitators and barriers to inclusion often focused on schools [2], included adults only[7], or participants of these studies only included students with physical disabilities [8]. It is thus critical to explore how inclusion can be facilitated or prevented in a community setting for children with developmental/mental health challenges and their families. This community-initiated project aims to explore barriers and facilitators to inclusive aquatics programming for children with developmental and/or mental health challenges.

Methods

This study adopts a participatory action research (PAR) framework, where participants make meaningful impacts on their own health through self-reflective inquiry and collaboration with other community members[9]. It puts an emphasis on lived experiences and sharing of power between everyone involved in the research and aims to empower individuals to enact the change that they hope to see in the community. In September 2019, the executive director

(MT) of a local nonprofit organization providing accessible aquatic exercises for people with disabilities was contacted by parents who have children who are neurodiverse and inquired about inclusive aquatic services. Realizing that currently no integrative aquatic programs existed in the community, MT reached out to TJ, professor of occupational science and occupational therapy at the local university to find out the best way to conduct studies on inclusive aquatics. Together, the community organization and parents partnered with an academic institution on this project (September 2019 – August 2020). The community and parents met once a month to discuss progress of the study. The partnership is ongoing as the nonprofit organization would like to implement findings of the study to develop a new program for children who are neurodiverse.. Neurodiversity here pertains to any developmental and/or mental health conditions such as autism spectrum disorder, Down syndrome, fetal alcohol syndrome, etc. Both parents and community program organizers are co-authors of this research. The nonprofit organization initiated the study and was involved in framing the research question, the study design and results interpretation (AW, MT). Parents who are co-authors were involved in data collection and results interpretation (JE, KA). Academic partners were involved in study design (KX, TJ), and conducting interviews/focus groups (KX). All authors were involved with drafting and revising of the manuscript.

Following ethical approval from the university's Behavioural Research Ethics Board, participants were recruited through convenience sampling. Direct emails were sent to relevant organizations and service provider registries. Posters were displayed in community centres, clinics, and schools. Study and recruitment details were also made accessible online. Inclusion criteria involved being 19 years of age or older, English-speaking, and belonging to at least one of three major stakeholder groups: family members or caregivers of children who are neurodiverse; helping professionals (therapists, educators, etc.); and community staff who have at least one year of experience programming for children who are neurodiverse.

There were 14 participants in total (see Table 1). Community staff (CS) had range of experiences, from providing swim instruction to program planning and implementation. Helping professionals consisted of behavioural interventionists (BI) and occupational therapists (OT).

Table 1: Participant descriptions

Participant	Category	Role(s)	Age	Gender	Experience
1	Parent/caregiver	Mother	41	Female	17 years
2	Parent/caregiver	Mother	47	Female	17 years
3	Parent/caregiver	Mother	45	Female	N/A
4	Parent/caregiver	Mother, researcher	50	Female	12 years
5	Parent/caregiver	Mother	38	Female	N/A
6	Parent/caregiver	Mother	37	Female	9 years
7	Community staff	Program planner	41	Female	11 years
8	Community staff	Program planner, swim instructor, manager/ administrative worker, teacher/education paraprofessional	28	Female	12 years
9	Community staff	Program planner, manager/administrative worker	33	Male	15 years
10	Helping professional	Behavioural interventionist	42	Female	20 years
11	Helping professional	Behavioural interventionist	27	Female	6 years
12	Helping professional	Behavioural interventionist, prior experience as swim instructor	32	Male	12 years
13	Helping professional	Occupational therapist, prior experience as swim instructor, pool rehab assistant	30	Female	14 years
14	Helping professional	Occupational therapist	55	Female	35 years

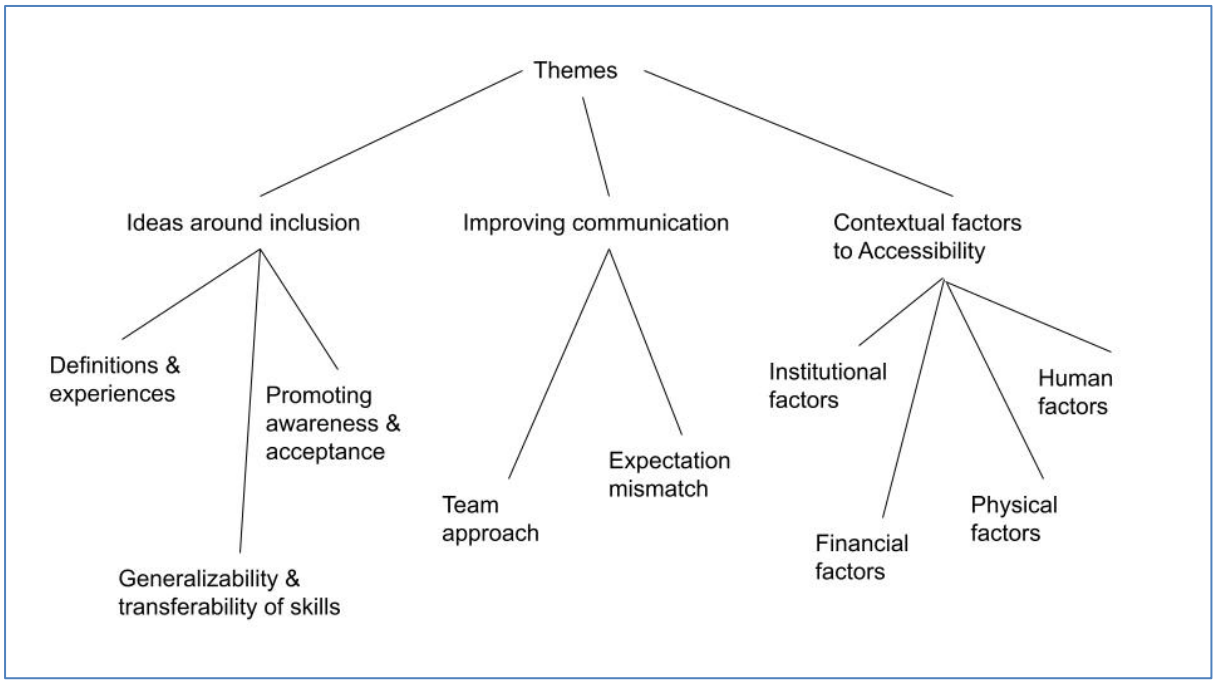
Two researchers facilitated focus groups, while one researcher conducted individual in-person and phone interviews. Most focus groups and interviews took place face-to-face, before transitioning to phone interviews due to COVID-19 restrictions. Prior to COVID-19 restrictions, when scheduling conflicts arose, interview instead of focus groups were offered. The mainstay of data collection switched from focus groups to phone interviews. In total, there was one focus group with four helping professionals, two in-person interviews with a parent and community programmer, and eight phone interviews with the remaining participants. Focus groups and interviews followed a semi-structured format. The same interview guide was used for focus groups and interviews. The interviews lasted between 30 to 60 minutes while the focus groups lasted 90 minutes. Sample questions asked included: "What does inclusion mean to you?" and "Why is it important for you to have inclusive programs?" See Appendix for Interview Guide used. All interviews were recorded and transcribed verbatim.

Data were analysed using Braun and Clarke's[10] (2006) phases of thematic analysis. Analysis was an iterative process, occurring after each focus group or interview, to allow researchers to identify with emerging ideas and knowledge gaps. Preliminary themes were discussed with the team to establish consistency. After all interviews had been coded, the themes were reviewed and refined with subthemes. The initial draft of results was sent to all participants for feedback. Two virtual focus groups were held for a "member checking process", with 6 participants in total Participant feedback was incorporated into the final results.

Results

Thematic analysis revealed three broad topics that participants addressed in their interviews: ideas around inclusion, improving communication, and contextual factors to accessibility (see Figure 1).

Figure 1. Framework for understanding barriers and facilitators to inclusion in community aquatics programming



Ideas around Inclusion

Definitions and Experiences

Participants expressed varying ideas of inclusion. While some felt that increased social interaction with typically developing peers was an important component, others emphasized meaningful participation independent of peers. Several service providers supported the concept of universal design, where the program is structured to allow all children to participate without the need for specific adaptations. Others believed that a specialized aquatics setting was necessary to build essential skills first. This difference stemmed from

concern for the child's safety - particularly in cases of understaffing - as well as not having enough trained staff to teach children who are neurodiverse. Parents and caregivers generally spoke more to the experience of the child themselves - for the child to feel included, they should be able to enjoy activities without perception of judgement or inaccessibility. Experiences around inclusion appear to exist on a spectrum and do not necessarily reflect physical inclusion. Some participants even felt that children may feel more included in a "segregated" program where they can relate to peers facing similar challenges. Parents, too, also feel a greater sense of community when they interact with other families who understand their struggles. Although there was no consensus around a single model of inclusion, all participants felt that an inclusive program should be equipped to support the unique needs and goals of each child and be able to adapt when necessary.

Furthermore, inclusion is not simply being present in a group environment, but also involves being effectively integrated into the same activities. Both caregivers and service providers expressed dissatisfaction towards situations where a child is left solely to the care of a support worker but is not actually included with the group in a meaningful way: "[My daughter's] school says that they're an inclusive school [...] it's just her thrown in with the regular students but [...] she's not able to integrate with anybody" (SS, parent). Participants believed the support staff should be available for everyone in the class so that the child who is neurodiverse does not feel singled out.

Generalizability & transferability of skills

Many participants believed that the benefits of inclusion programs extend beyond the program itself. Fostering connectedness not only improves the child's experience of the activity, but also enhances their capacity for social growth. As many service providers

expressed, the purpose of an inclusive aquatics program is to enable children to eventually swim in any social or physical environment:

> I would see inclusion being, excuse the pun, but a springboard, like aquatic classes being a springboard to say, as I get older, maybe I want to go sailing […] You open up all those other doors because you've been inclusive in one activity when you're starting young" (Elizabeth, OT)

Many participants noted that children who are neurodiverse often have difficulty adjusting to change, such as switching to a different pool or instructor. The goal, then, would be to help the child achieve a level of comfort and competency where they are able to adapt to these changes with more confidence and swim in unfamiliar settings. Apart from water safety, the skills developed through interacting with peers, experiencing novelty, and building competency can generalize to various other contexts and set the child for success in the future.

Promoting awareness and acceptance

Public awareness around inclusion has significant implications on the success of programs. Participants felt that education around inclusion should be offered at a young age. Some shared stories of children being bullied at school or not being invited to birthday parties; these experiences were particularly distressing for caregivers, who worried about the impact on their child's self-esteem. Several parents also spoke about feeling embarrassed in public when their child exhibited problem behaviours, or afraid for their child when their need for additional space was disregarded. This made it difficult for them to safely and comfortably access drop-in spaces where other parents, rather than staff, were responsible for supervising their own children. As one service provider described, inclusion is more than a condition of general acceptance; it requires action at individual and societal levels. Promoting inclusion in

community settings set the example for children and the public alike that inclusion is not only the responsibility of schools:

> If some sort of public awareness program is created for disability […] and the traction that has gained at the public level, that could help with not only parents who may need to disclose that their child needs some extra help, but also parents who look down on those children as a disruption to the program. (Xamus, CS)

Improving Communication

Team Approach

All participants experienced barriers to communication and expressed desire for a team approach. As Katie (parent) suggests, programs should "set up a protocol for each child [...] to give that to volunteers ahead and also prepare the child." Participants appreciated and advocated for opportunities to communicate expectations before the program, during, and after. Encouraging open dialogue between parent and instructor not only eases parental anxiety around enrolling their child in the program, but also assists the instructor in tailoring the lesson around the child.

Service providers should take care to consider power dynamic that exists between caregivers and service providers as it can be a barrier to these important interactions. Several parents described hesitancy to advocate for their child's needs out of fear that their feedback may be received poorly:

> I tend to speak my mind. But when it comes to him, to my son, I have to weigh a lot of things. Cause okay, if I speak up, how is [the instructor] going to take it? If he takes it as if I'm interfering - some people really don't like being told what to do or suggested what to do - then would my son's life be even harder? (Aly, parent)

Participants suggested ways to empower parents and facilitate parent-provider collaboration through offering different modes of communication (e.g., anonymous feedback forms).

Many participants felt that there is a need for a collaborative effort between healthcare professionals, community staff, other service providers, and families. Helping professionals believed that their professional advice should be consulted for various aspects of program implementation and delivery, as Brittany (OT) said: "I think I would like everyone to know what OTs are […]. It would be amazing to have OTs more involved in the program development and training and life."

Participants desired continuity of communication, particularly when transitioning to a new instructor. Another communication barrier relates to organizational decision-making and its downstream impacts on service delivery. As Brandon (BI) noted, higher-level staff are removed from daily interactions with children and families and thus may not adequately address existing problems: "[The people who get to make decisions] they're so far removed from everyday struggles and everyday needs that they're not necessarily making the policies that fits the need." Facilitating communication across organizational levels, while incorporating input from families themselves, is necessary to bridge this gap.

Expectation Mismatch

Parents described situations where programs were not suited towards their child's unique goals or needs. For instance, some may expect skill building rather than socialization with peers. One parent expressed preference for a one-on-one approach over a group class as it allowed their child to develop swim techniques more efficiently. Another parent, however, wanted their child's program to include more group activities so that there was opportunity for peer interaction. Clarifying these objectives in advance may clarify expectations.

Service providers also spoke of stressful instances where parents enroll a child who may require additional support in a typical program without notice:

> We've had to segregate, making a private lesson for example, for a child or parent that wasn't aware that it was a regular lesson program and we didn't have the staff to facilitate it […] (Kate, CS)

These situations typically result from parents either not being given a chance to disclose their child's needs, or not wanting to accept that their child requires extra help. In the latter scenario, service providers described how parents may be defensive when issues around their child's behaviour are brought up. Tying in with the theme of promoting awareness, addressing the negative stigma that parents themselves have towards their child's condition is critical to removing this communication barrier.

Another concern arises when a child accessing adapted lessons doesn't require the additional support and may in fact succeed in a general swim program. One programmer felt that families may become dependent on adapted programs and may be unwilling, or anxious, to put their child into a regular class even when the child has progressed to be able to succeed in them. One parent explained that much of their hesitation comes from fear of losing their spot in the adapted program if the new program is unsuccessful. The mismatch in expectations between service providers and families again stemmed from lack of communication and makes for an inefficient system where waitlists can unnecessarily accumulate.

Contextual Factors to Accessibility

Institutional Factors

Complicated registration process. As several parents recounted, program intake process often required an in-person assessment which made registration more challenging.

Additionally, programs may grant earlier registration to previous participants, making registration competitive for new participants.

Inconvenient timing. Parents talked about how lessons are typically offered during rush hour or dinner time, or when they are at work. Service providers noted that these times were chosen due to availability of volunteers, highlighting a gap in the hiring of more qualified personnel. Programs themselves are often quite short – half an hour or so, with little room in between to transition smoothly – making it difficult to justify long travels.

Poor marketing. Parents expressed difficulty navigating community sites or brochures to find inclusive programs, relying instead on word-of-mouth and their therapists' referrals. Service providers explained that community centres are hesitant to broadly advertise programs where sufficient resources or supports are not guaranteed.

Human factors

Staff training. Some parents shared negative experiences around having poorly trained instructors or volunteers, resulting in limited progress in skill development or even jeopardized safety. Service providers, many of whom have experience instructing classes, feel that the training offered to staff is too generalized and taught ineffectively. Current training programs would benefit from having a licensed professional, such as an OT, teach strategies specific to various special needs and scenarios. Families are often stuck trying to fit their child into activities that do not match their competencies:

> When I try to register [my son] in the regular programs, for me to put him into a group of kids at the same chronological age as him, he cannot follow. But then when I inquire about, can I put him in a group of kids with lower ages, it's not possible because he's three years older or five years older […] But then, when I put him in the

special needs program, the programs are usually dumbed down so far it poses absolutely no challenge." (Aly, parent)

Where introducing an array of new programs may not be immediately feasible, existing programs should provide more flexible options for children to participate. One parent provided an example where instructors can give adapted activities for half the class and typical activities for half the class and then rotate so that their child may feel included.

Instructor-Participant Ratio. General swim programs involve one instructor to numerous students, making it difficult to attend to a child needing more support. Participants shared experiences of successful programs having an increased staff to student ratio, where additional staff are not necessarily assigned to one child but rather the whole group.

Caregiver capacity. Parents expressed frequent feelings of burnout, particularly when they had to balance work and care for siblings in addition to attending to their child with other needs: "[w]hen [my child]'s not able to participate in things... it ties up all of my time basically trying to keep her entertained by myself and find things that will keep her busy." (SS, parent). Being able to drop their child(ren) off in an inclusive program often meant respite for parents. Siblings of neurodiverse children may also feel neglected. Several parents described positive experiences where siblings were enrolled in the same program, either as another participant or a volunteer. Providing the option for siblings to enroll in the same program can thus help to simultaneously address issues of caregiver burnout and the siblings in the household.

Physical factors

Pool Environments. Parents expressed concern over cold water temperatures, noise levels, large pools, and busy crowds, factors which complicate an already stimulating environment for the child. Service providers also noted the lack of consistency in equipment and

infrastructure between pools. Suggestions include having a gradual ramp to ease transition into different water levels and reducing class sizes, planning lessons during times where there is reduced public traffic or restricting public access during lesson times.

Geographical barriers. Due to the limited availability of existing inclusive programs, families often must travel from afar for their child to participate. For some families, the travel distance may not be feasible considering time constraints and opportunity costs. Offering programs at more widespread locations, or at a larger central location, may help to alleviate some of these challenges.

Financial factors

Cost-benefit. Several parents and healthcare professionals also spoke to how families often decide between enrolling their child in community programs or therapy – both potentially costly services in the absence of any subsidization. At the municipal level, a restrictive budget poses a barrier to offering more programs and resources. Increased funding, whether to support single households or communities, thus appears to be a critical component to improving inclusive practices.

Discussion

From the one focus group and ten in-depth interviews, three central themes emerged: definitions and experiences of inclusion, need for improved communication, and contextual factors to accessibility. Discussion around these themes revealed that the major barriers to inclusion include the variability in inclusion experiences, social stigma, and lack of support or resources. Major facilitators, on the other hand, include longitudinal relationships, program flexibility, collaboration between stakeholders, and staff members' and families' own confidence.

Interestingly, not all participants identified physical inclusion as ideal or truly inclusive in community programs. Parents, in particular, expressed more concern with having a classroom model of inclusion in an aquatics context. They voiced concerns about lack of skill progression with typical peers, difficulty fitting in, and also feared public scrutiny. A recent study on parental perspectives of their child's transition into inclusive fitness settings found that fear of judgement and inadequate preparation constituted major sources of anxiety [11]. Chen and colleagues[12] also found that even within an "inclusive" preschool program, children tend to interact with those with similar language capacities, and those with language difficulties spent significantly more time alone. This may explain why studies on outcomes of inclusion and group participation have not consistently demonstrated improvements in social skills[13]. As several participants in the present study mentioned, there is a need for staff and peers to actively engage children who are neurodiverse in group activities.

For service providers, the primary concern appeared to be lack of staff capacity and potential safety risks. Aherne and Coughlan[14] interviewed staff from an adapted aquatics program and found similar concerns, along with time and financial constraints. Another study found that aquatics instructors preferred teaching students with milder disabilities, and that having more staff certifications was the strongest predictor of favourable attitudes towards including children with severe disabilities in regular programs[15]. The current study supports bidirectionality between staff motivation and staff readiness, suggesting that increasing staff capacity and confidence in teaching children who are neurodiverse may result in increased willingness to facilitate inclusive environments.

Children who are neurodiverse routinely participate in fewer physical activities compared to their peers, and do not meet daily recommendations[16]. One study with older adults who are neurodiverse, also using focus groups and interviews, found that lack of confidence and skill was a significant barrier to physical activity[16]. The limited access to

inclusive opportunities for children, as described by participants in the current study, can have negative downstream effects on participation during adulthood. Given that potential improvements in motor and social skills may be retained after the end of an aquatics program, fostering this growth early on is key to influencing children's life trajectories[17].

This research contributes understanding of inclusion in aquatic and other community-based contexts. Current children's aquatic programs often provide a report card at the end of the lesson set, where the instructor decides whether the child passes the current level and can advance. Our research calls for exchanging normative swimming standards in favour of more open definitions of success. Community programs can empower parents and instructors alike by providing regular opportunities for open communication between them, which may prevent communication breakdowns and ease potential anxieties or cognitive barriers. The community organization involved in this research is planning to apply the findings from this research to trial a new program model called "Aquatic Literacy", where a child who is neurodiverse enrolls in a typical swim program with neurotypical peers with the flexibility of having a trained personnel who can work with the child when one-on-one time is needed. The program will be taught with one instructor and a support personnel who has training on working with children who are neurodiverse. The child who is neurodiverse will spend at least a portion of the time (as a goal set with parents at the beginning of the program) with the group and receive one-on-one time when necessary. This program framework will be trialled once pandemic restrictions are lifted. This model may be applicable to many community physical and leisure activities to promote inclusion.

Limitations

The sample size was not large enough to conduct more robust qualitative analysis. However, within the small sample, representation from different stakeholder groups was

relatively balanced. Furthermore, generalizability is not a guiding principle in qualitative analysis. Data saturation was reached near the end of the data collecting session, indicating that the primary concepts had been explored. Data collection also relied more heavily on phone interviews rather than focus groups as intended due to the pandemic.

Conclusions

This study explores the various factors, in the perspectives of parents, service providers, and helping professionals, that influence inclusion in community-based aquatics programs. The findings show that while people hold different opinions on what inclusion means, major facilitators and barriers to inclusion are universally acknowledged. These factors range from an individual scale, such as families' financial circumstances, to a larger societal scale such as stigma around disability. This knowledge will inform policymakers and program administrators on how to facilitate better inclusion within the community, through appropriate resource allocation and improvements to service delivery.

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THE UNIVERSITY OF BRITISH COLUMBIA

Department of Occupational Science & Occupational Therapy
Faculty of Medicine
T325 - 2211 Wesbrook Mall
Vancouver, BC Canada V6T 2B5

P: 604 822 7392 | F: 604 822 7624
os.ot@ubc.ca | www.osot.ubc.ca

Inclusive Community Program - Aquatics (ICPA): FOCUS GROUP / INTERVIEW GUIDE

The purpose of the focus group / interview is to understand your perceptions of the barriers and facilitators to inclusive community programs for children. We are conducting a qualitative research project on this topic and your input would be greatly appreciated.

FOCUS GROUP

- In order for us to freely share our thoughts and ideas, we ask that you not share anything said in this focus group to others.
- Our conversations would be recorded and transcribed. However, the only people who have access to this information would be the research team.
- The format of this focus-group involves us posing questions to the group and asking further probing questions. You have the option of not answering any questions that you are not comfortable with.
- The group will last no more than an hour and a half. If you have any questions after this focus group, feel free to connect with us via email or phone – contact information is provided on your copy of the consent form.
- Do you have any questions before we get started?

INTERVIEW

- What is said and discussed in this interview will remain confidential.
- Our conversations will be recorded and transcribed, however, the only people who have access to this information would be the research team.
- We ask that you respect each others' privacy by not disclosing the contents of this discussion outside of the focus group.

Version 2.0
10/24/2019

- This interview involves us asking you probing questions, and will last for about an hour to an hour and a half.
- If you are not comfortable answering any questions, just let us know and we will move on.
- If you have any questions after this interview, feel free to connect with us via email or phone– contact information is provided on the consent form.
- Do you have any questions before we get started?

SAMPLE QUESTIONS

1. What does inclusion mean to you?

2. Would you say that the program you work in (or your child participate in) is inclusive? Why or why not?

3. When you imagine an inclusive community based program for your child/children you work with, what does it look like?

4. Why is it important for you to have inclusive programs?

5. What do you wish others would know about inclusion?

6. In your role as a _____ (parent, therapist, teacher, etc), how do you think inclusion may be facilitated in a community program for children with mental health challenges?

7. In your role as a _____ (parent, therapist, teacher, etc), how do you think inclusion may be hindered in a community program for children with mental health challenges?

8. What might be some barriers or challenges that you could face if you are trying to foster an inclusive environment with children with mental health challenges?

9. What can you do to facilitate inclusion for children with mental health challenges?

* These questions will build upon preliminary concepts and themes that are formed after the preliminary data analysis.