



# **Parent WhatsApp groups in an early intervention community-based program in rural South India during the COVID-19 pandemic: a pilot study**

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# Reach & Impact



**> 1,50,000 Children Screened**



**> 6500 Health and Education workers trained**



**> 6000 Children impacted with therapy**



**> 18,000 Caregivers Empowered**



**> 1,20,000 people with reduced stigma**



**More Inclusive Society**





# Social Support



Parents of children with disabilities often lack social support.

Parent support groups are beneficial for sharing experiences and mentoring other parents.





# Study Objectives

1. To explore the **feasibility of WhatsApp support groups** to facilitate **knowledge sharing** for and between parents of children with disabilities.
  1. To explore if **WhatsApp** groups is a good medium to facilitate peer support and mentoring between parents of children with disabilities.
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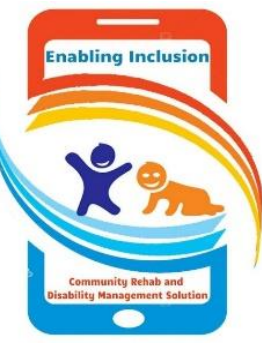




# WhatsApp Group Logistics



- **Two WhatsApp Groups were formed:**
  - (a) Parents of children with primary motor delay and impairments
  - (b) Parents of children with primary cognitive and/or communication disorders
- Each group was **facilitated by a rehab therapist** from the Enabling Inclusion® program
- **Weekly or 2x/week postings for SIX weeks**



# WhatsApp Group Topics



- **A weekly theme** related to International Classification of Functioning, Disability and Health (ICF) and Family Centered Services (FCS) was presented
- **NINE different module topics**
- Content related to **engaging families** in developmental services





# Module Topics



என்னுடைய குழந்தையின் குறைபாட்டுக்கு

நான் காரணம் இல்லை.

எனக்கு தெரிந்த அளவில் என்னுடைய சக்திக்கு ஏற்ப

என் குழந்தைக்கு சிறந்ததையே நான் செய்கிறேன்

1. Friendship for children with disabilities
2. The importance of play
3. Avoiding parental /self blame for child's impairments
4. Child support from all family members
5. Parental understanding of intervention and support



# Module Topics



பொதுவாக ஒரு குழந்தையின் வளர்ப்பில்  
ஒரு குடும்பமே பங்கேற்கிறது.  
குறைபாடுடைய நம்முடைய குழந்தைகளுக்கும்  
குடும்பத்தின் அன்பு, அரவணைப்பு  
மற்றும் கவனிப்பு தேவை.

6. Guidance and teaching of self care activities

7. Benefits of fitness and exercise

8. Assistive devices and adaptations for  
children's independence

9. Respecting individuals, no matter their age  
and abilities

# Presentation and facilitation of module



- **Information** was presented in writing (Tamil) with **supportive pictures** and **voice messages** by group facilitator
- After each message, **questions were posted** to initiate conversation
- **Parents discussed topics** and **facilitator provided clarifications** and introduced new topics based on the theme of the week.





# Study Timeline



- The study was conducted during the COVID-19 pandemic **period for four months from March to June 2020.**
- **Study Timeline:**
  - 3 weeks for preparation and formation of groups and content
  - 6 weeks for posting
  - 3 weeks for interview and translation
  - 3 weeks for reporting



# Methods

## Mixed Methods Interviews



### Sampling

**Purposeful sampling across parents** who posted frequently, less frequently, not at all and those that dropped out.

- **Phone interview** (survey questions)
- **Qualitative interview of parents** on parental experience, engagement, challenges and benefits and to identify possibilities for improving the WhatsApp groups.





# Qualitative Interview with participants



**The interviews were divided into three categories of questions:**

1. Access and engagement with the WhatsApp posts
2. Expectations and relevance of the WhatsApp posts
3. Peer support





# Results

**Recruitment:** Out of 804 active service user parents, 174 joined one of the WhatsApp groups. Majority of families who did not join cited lack of smart phone and/or data plans as reason for not joining.

## Group A

(Parents of children with primary motor delay and impairments)

- ❖ 118 parents joined the group initially
- ❖ 34 parents dropped out of group during study
- ❖ 20 parents interviewed
- ❖ 63% mothers, 26% fathers, 5% aunt and 5% both parents were interviewed

## Group B

(Parents of children with primary cognitive and/or communication impairment)

- ❖ 135 parents joined the group initially
- ❖ 39 parents dropped out of group during the study
- ❖ 13 parents interviewed
- ❖ 62% mothers, 38% fathers







# Results - Access and Engagement



- In 79% of households interviewed, the **father was the primary user of smartphone.**
- Despite that, mothers participated the most often: **72% of discussion posts were from mothers.**
- 56% of parents **read all posts**, 40% of parents **read most of the posts**
- **High level of parental engagement** including reading, replying to posts and discussion were seen.





# Results - Expectation and Relevance



- 86% of parents felt group met or exceeded initial expectations

Relevance to their situation and/or child's development:

- 44% of parents felt majority of the posts and discussions were relevant
  - 28% of parents felt some of the posts and discussion were relevant
  - 28% of parents felt majority of the posts and discussion were not relevant
- 
- Parents who dropped out cited getting unwanted forwarded messages that were not relevant to discussion points in the group, as the reason.





# Results: Reasons for Engaging

Interviews identified reasons for varying levels of engagement, among those:

- Household priorities
- Emotional response to posts
- Interest levels
- Relevance of posts/discussion to their child's condition
- Ability to connect to data networks.







# Results: Peer Support



- 96% of parents felt WhatsApp group was a good way to increase peer support
- Interviews revealed that for the majority of parents, this was their first time accessing **any form** of peer group support with other parents of children with disabilities
- Suggestions for other way of peer support such as video chats, in-person meetings and better grouping of parents according to match their children's need were made





# Discussion



- Positive impact of the social media group were seen,
- Improved peer connections,
- Improved Information sharing to/between parents,
- Improved peer sharing
- Improved knowledge and motivation to increase child participation and inclusion.
- Parents suggested greater matching of groups to participant's needs, impairments and age was seen.
- Parents suggested more varied posting including videos, e-pamphlets





# Next Steps!

*WhatsApp Groups continue within ASSA's Enabling Inclusion Program*

- **In person participant meeting** to encourage rapport building and group interaction prior to start of the group.
- **Sharing of preliminary information** regarding the group topics and participant protocols given prior to commencing the discussion.
- **Improved ground rules** on parental posts and forwarding of posts at the outset.







# Next Steps!



- **Creation of 6 smaller WhatsApp groups, matched more closely** to participants needs with regards to their child's age, impairments and development issues.
- **Creation of more video content and e-pamphlets** for parents to follow and to stimulate discussion





# Moving Forward



- **Motivate parents** to be confident in the groups and ask more questions/share more information
- Provide the opportunity for parents to develop better **peer connections outside of these groups**
- Develop a later-stage study to expand on the current information and further analyze parent outcomes from this method of **parent peer support group**





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