



Parent WhatsApp groups connect families in a community-based program in a rural South India: A pilot study

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Background

The UN's Convention on the Rights of Persons with Disabilities (CRPD) affirms the fundamental rights of all children with disabilities (CWDs) to human rights inherent to all children, including the provision of information, services and support to families of children with disabilities. Amar Seva Sangam's (ASSA) Early Intervention (EI) program serves more than 2500 children with developmental disabilities, Tamil Nadu. Developing peer support is an important component of family-centred service (FCS) and an earlier study in this setting highlighted a lack of opportunity for peer connection amongst parents in the home-based program, and its detrimental effect on inclusion of their children with disabilities.

Objectives

To explore the feasibility of using the WhatsApp social media platform to connect and promote interaction between parents receiving home-based EI services in rural Tamil Nadu, India.

Methods

This pilot study was a joint project by between ASSA, a Canadian Disability Studies masters' student-researcher, Canadian consultants from Handi-Care Intl, with mentorship from faculty at the Harvard Centre on the Developing Child.

Parents Whatsapp Group

No of Groups:

Two whatsapp groups were formed one for the parents of children with motor delay and impairments and the other group is for parents of children with cognitive and communication delay.

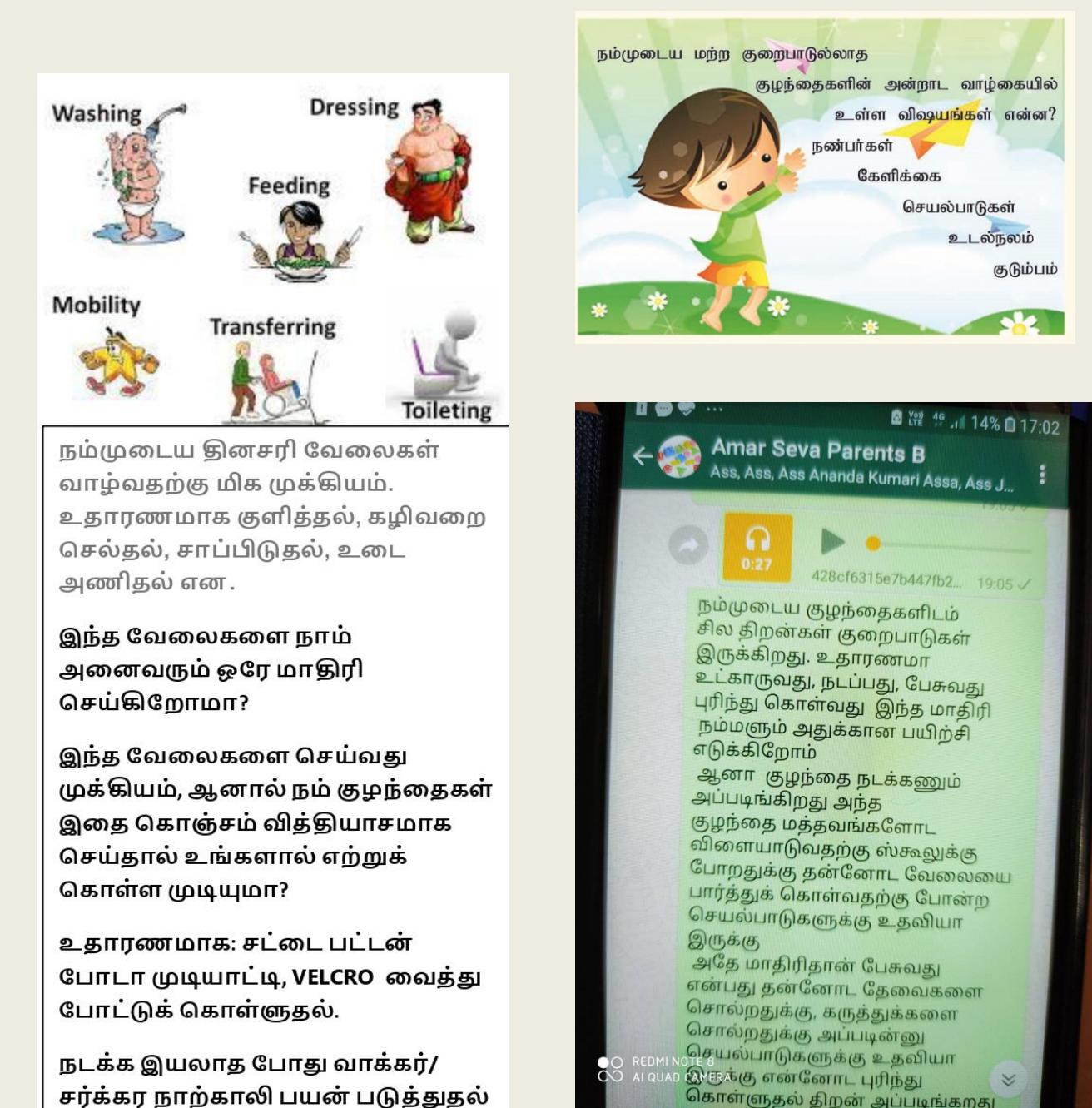
Topics:

Since we cover parents of children with various impairments in the same group, we chose and discussed the common topics like Family Centered Services and International Classification of Functioning, Disability and Health. We prepared 9 modules to post in each week.

- Friendship for children with disabilities
- The importance of play
- Avoiding parental blame for the impairments
- Child support from all family members
- Parental understanding of intervention and support
- Guidance and teaching of self care activities
- Benefits of fitness and exercise
- Assistive devices and adaptations for children's independence
- Respecting individuals no matter their age and abilities

Presentation of module:

Information was presented in writing (Tamil) with supportive pictures and voice messages. After each message, questions were posted to initiate conversation. Then address the clarifications, introduce new conversation based on the theme concepts.



Duration of the study

This study was conducted during COVID pandemic period for four months from March to June, 2020. Approximate time for the activities were

- 3 weeks for preparation and formation of group
- 6 weeks for posting
- 3 weeks for interview and translation and
- 3 weeks for reporting

Interview with participants of whatsapp group

The objectives of the interview questionnaire were:

1. To understand parents' experiences with the WhatsApp groups
2. To Identify possibilities for improving the WhatsApp groups

The benefits of parents participating in this questionnaire were:

- Opportunity to contribute to program improvements •
- Sharing information about child development and family centered services

The interviews were divided into four categories of questions:

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

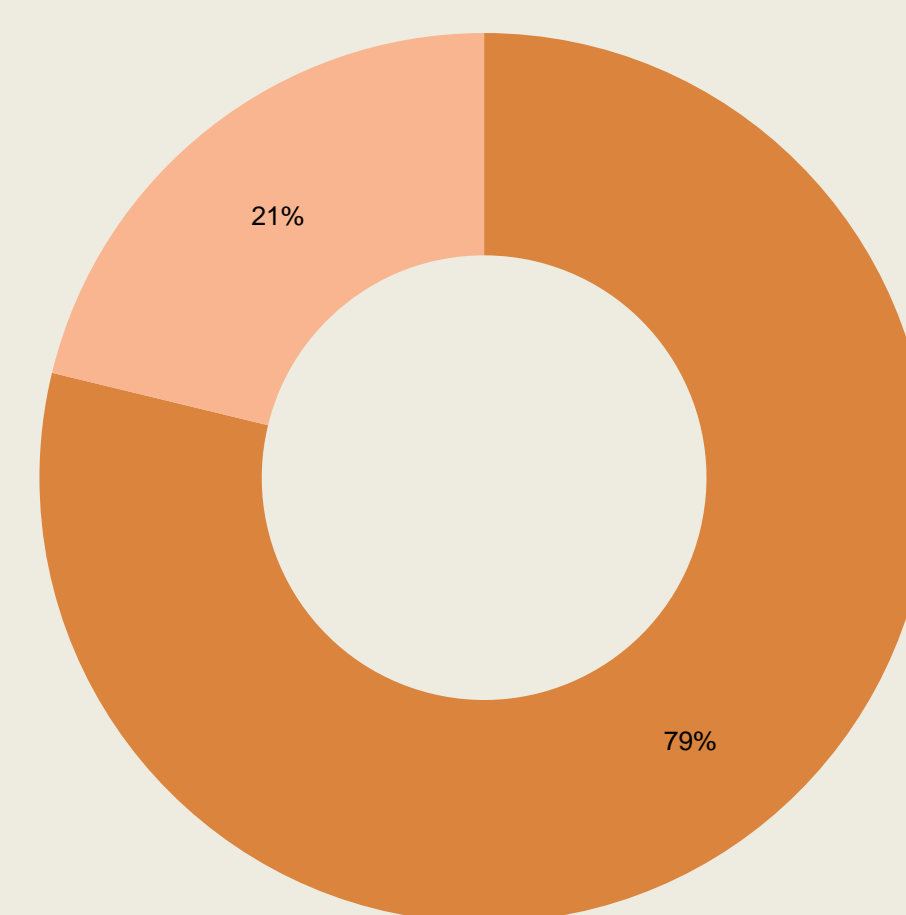
Results

1. Recruitment: Out of 804 active service user parents only that access to smart phone and WhatsApp were joined. 174 parents joined in the group.
2. Total participants in each group:
 - Group A:
 1. Recruitment: 76
 2. 20 parents interviewed (21% interviewed)
 3. Demographic Data: 63% mothers, 26% fathers, 1 aunt (5%) and 1 family had both mother and father speak (5%)
 - Group B:
 1. Recruitment: 98
 2. 13 parents interviewed (13% interviewed)
 3. 2) Demographic Data: 62% mothers, 38% fathers 3)

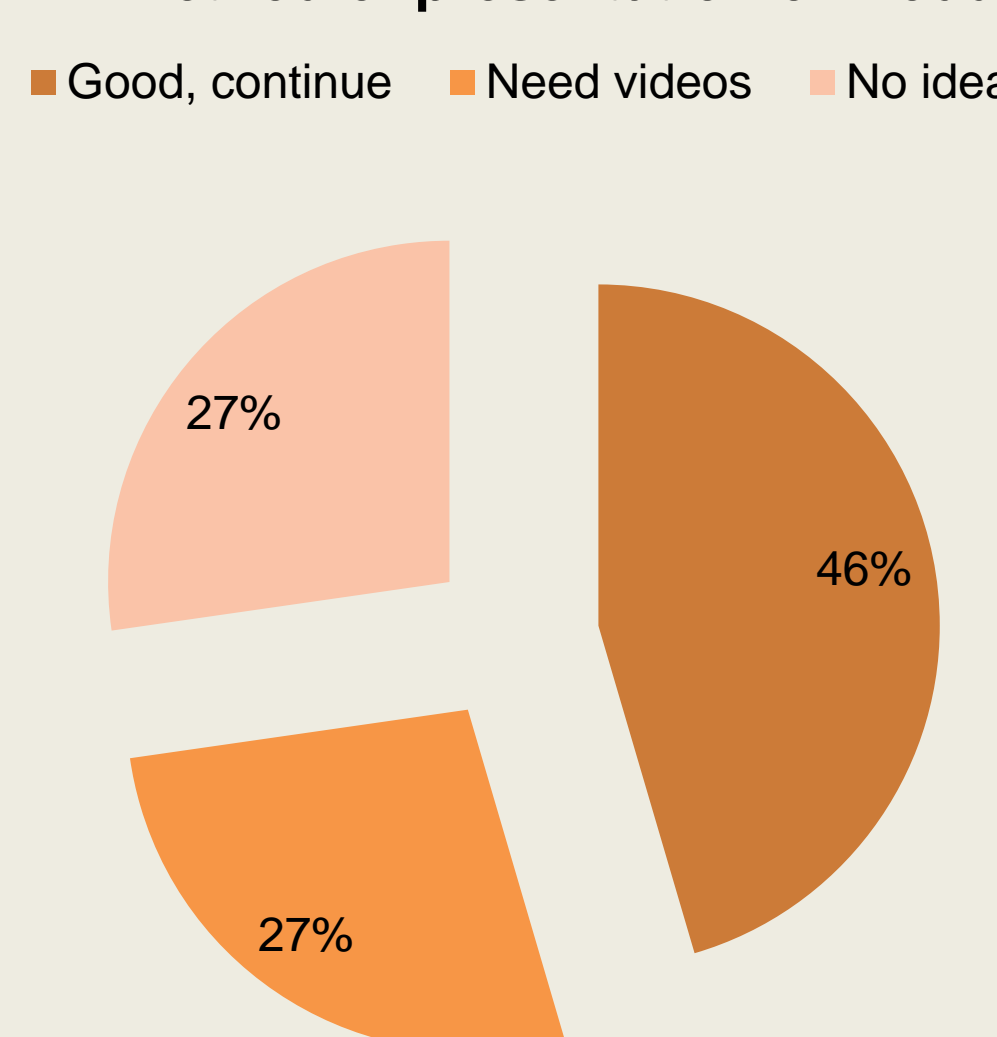
Access to smart phone

Only 21% of the mothers have smart phone and can see the postings with notifications. In spite of that, mothers being the most common parent to participate. High parental engagement levels involved reading, replying to posts and discussion. Interviews identified reasons for varying levels of engagement including household priorities, emotional response to posts, interest levels, relevance of posts/discussion to their child's condition and ability to connect to data networks. Interview feedback revealed a positive impact of the social media group, improved peer connections, information sharing to/between parents, improved knowledge and motivation to increase child participation and inclusion. Participants recommended including parent facilitators and matching groups to participant's needs.

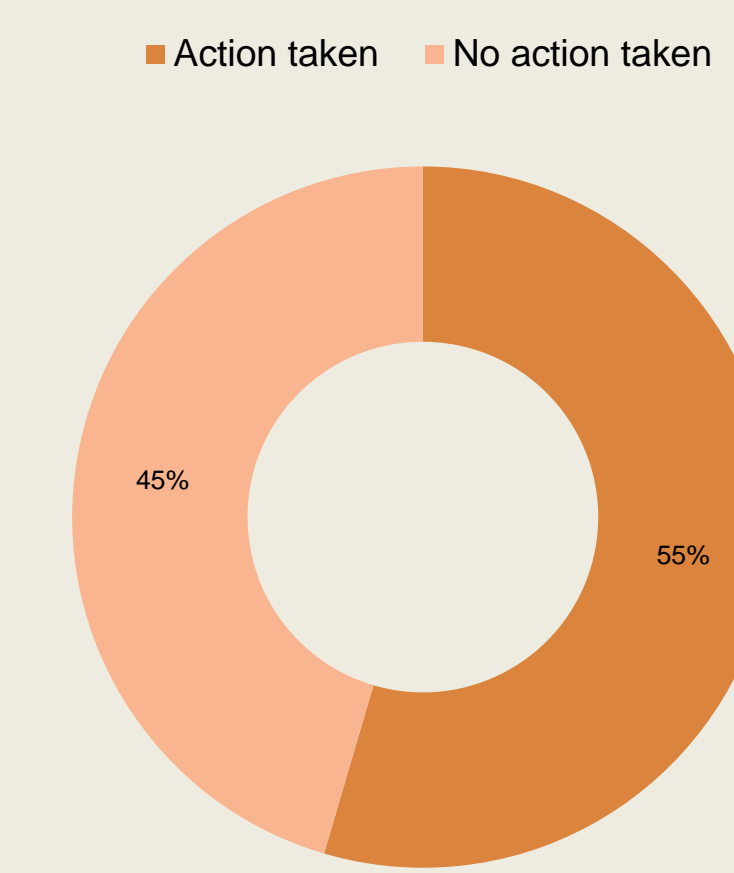
Smartphone ownership



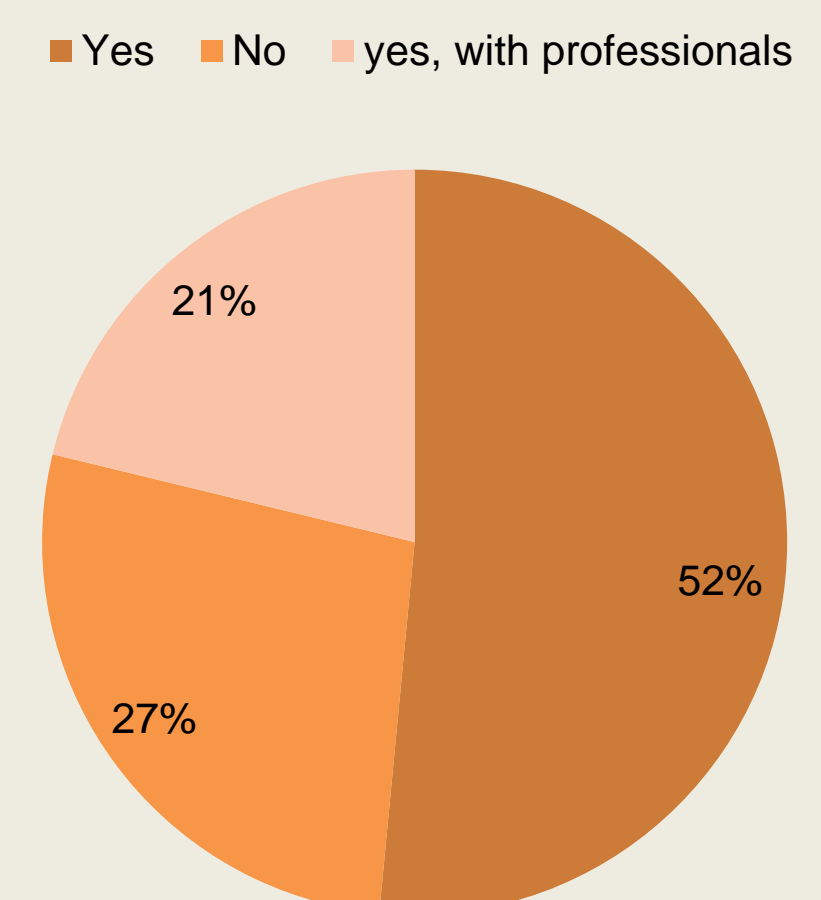
Method of presentation of Module



Implementing in life



Parents Facilitators



Conclusion

Parents WhatsApp group is a feasible method to connect parents for peer support and learning. Social media is an excellent tool to connect families to share lived experiences and resources while overcoming barriers of inaccessibility and geographical distance. Major barriers were access to smart phones and data connectivity. The study affirms the need to address the right to technology and internet connectivity for provision of equitable rehabilitation services to people with disabilities.

Parents suggestions for improvement:

- Preliminary information regarding the group topics and participant protocols prior to commencing the discussion.
- Wider scope of information to target all age groups and disabilities.
- Video tutorials displaying step-by-step methods for parents to watch and follow closely.
- Encouraging greater rates of parent participation by motivating and assisting them.

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