

Case Study

Community co designed Model – Enhancing self-care and socialization of children with Autism Spectrum Disorder in Northern Province, Sri Lanka

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Autism Spectrum Disorder (ASD) challenges the children and caregivers or family members in life skills development, socialization and learning. Community-based early interventions are evidence for adaptive behaviors and skills development towards school life of these children. The aim of this case study was to develop an implementation strategy according to the local context with evidently proven management methods to enhance self-care and socialization among the children with ASD in Northern Province (NP), Sri Lanka (SL), through qualitative framework analysis. The participatory action research methodology was used. Fifteen children and their family members were followed up for 1.5 years. Through structured play activities, skills development and behavioral changes were observed. Focus group discussions and face to face interviews with parents were used as evaluation methods. During the follow up, significant improvement in self-care and socialization was observed with the whole family approach and trained supportive team. It can be concluded that the caregiver empowerment along with a trained supportive team as implementation strategy to enhance the self-care and socialization of children with ASD in NP, SL.

INTRODUCTION

ASD is the condition with developmental delay or disability which shows social, communication, and behavioral challenges in the lifecycle¹. Self-care, socialization, and learning are the major hurdles for these children. It was evidently proved that the support of child-center play activities showed several beneficial effects on skill development and it was considered as culturally responsive counseling intervention for children².

Play therapy is a systematic use of a theoretical model with trained personals and therapists to overcome psychosocial difficulties for optimal growth and development³. Participation of family members was highlighted in several studies as building a bridge between an individual and society^{4,6}. Play Therapy facilitates communication, foster emotional wellness, enhance social relationships and increase personal strengths⁷. When considering the cultural competency is the major influence on developing diverse play activities and implementation strategy.

Among 5088 students who were in special education units of Sri Lankan schools 10% were ASD⁸⁻⁹. Having hurdles in learning progress is a huge challenge for the children with ASD and their family members which reduces the family's quality of life. They need external support to cope up with those hurdles¹⁰. But unavailability of approaches to get trained external support paved the way to create an implementation strategy according to the local context with evidently proven management to enhance self-care and socialization among the children with ASD.

OBJECTIVE

To develop a community co designed model to enhance self-care and socialization of children with ASD in Northern Province

METHODOLOGY

The study was conducted as framework analysis qualitative research among the registered patients with ASD in the pediatric center, Green Memorial Hospital, Manipay, Jaffna district by following Participatory Action Research (PAR)¹¹ methodology for 18 months (May 2020 to November 2021). The ASD children who are under 15 years and their family members were included in the study. Other neurodevelopmental disorders were excluded. Purposeful sampling technique¹² was used and sample size was 15 (5 girls and 10 boys). Six trained coaching assistants also participated in the study.

Parents of children with ASD approached the Consultant Family Physician for a solution for the behavioral issue of their children. They were invited to a forum to discuss with researchers. The expectation of parents was enhancing self-care and socialization. The researchers showcased the evidence of play therapy and designed structured play activities as intervention for children. Consultant Family Physician created an expert's team to train coaching assistants to conduct structured play activities, do follow-ups by shadowing the children in school and report the skills development or behavioral changes.

The study period (18 months) was divided into 6 terms. Each term (3 months) focused on steps of frame work analysis for strategy development¹⁵. Children were assigned with play activities and parents were trained to accept the child's status. End of each term, a focus group discussion was arranged with parents to reflect about children's development and their experiences. And coaching assistants were asked to share their feedback also. Organized training workshop for coaching assistants and face to face individual discussion with parents regarding next term's plan. The corkscrew cycles of engagement, involvement and reflection were continued till developing an effective behavioral change strategy. The detailed plan was tabulated in table 1.

RESULTS AND DISCUSSION

Familiarization

The comprehensive assessment was conducted to the children and their parents in term 1. Gross motor skill, fine motor skill, life skill, creative skill and pre learning skills were assessed as the baseline of self-care. According to their skill development stage and their interests, they were grouped for socialization activities.

To assess the baseline perception of the parents towards their children's ASD condition, the research group sensitized the parents by storytelling. Most of the parents expressed their perception towards ASD as a psychiatric condition. social stigma, financial stress, emotional stress, child's education, independency and caregiving burden of other siblings were addressed as consequences. Parents were motivated to understand and accept ASD by the research team.

Table 1: The term-based research procedure

Period	Plan of for children	Plan for parents
Term1 Familiarization	To do comprehensive assessment of children's skills development stage, behaviors and interests	To understand parent's expectations from their child and the influencing factors of their involvement
Term 2 Identifying a thematic framework	Plan with structured play activities for each developmental stages based on the ability to play	Plan for parental empowerment to provide continuous support to their children by considering their perceptions and influencing factors.
Term 3 Indexing	Implementing the plan with goal setting in behavioral change	Implementing the plan with goal setting in behavioral change
Term 4 Indexing	Face the challenges and improve the plan iteratively	Face the challenges and improve the plan iteratively
Term 5 Charting	Observation and evaluation on adaptation for the implementing strategy with adoptable behavioral changes and skills development	Feedbacks and evaluation on adaptation for the implementing strategy about their child's improvement and parent's involvement
Term 6 Mapping and interpreting	Finalize the implementing strategy	Finalize the implementing strategy

Identifying a thematic framework

Term 2 was designed to give the opportunity for the parents to involve and engage in designing play activities to explore the capabilities of their children and themselves with the help of researchers. Group and individual discussion ensured the success of play activity sessions. End of the term 2, reflection of the parents listed out the following challenges:

Challenge 1- to identify the correct stimulating play activity for behavioral change

Challenge 2- to give the continuous stimulation

Indexing

Term 3 indexed the challenges as goals to achieve and it was aimed to develop an action plan to create the implementation strategy with the above reflection. Research team organized monthly assessment for the child which helped to identify the correct stimulus play activity. To overcome the 2nd challenge, we found in Term 2, young girls were empowered as coaching assistants, and shadow teachers. The role of shadow teacher is very important in this juncture to teach self-awareness, goal setting, problem-solving, and decision making¹³. These young girls followed the children in school as shadow teachers in the mornings for four hours and in home as coaching assistants to fulfill the unique family needs at structured home environment. Further, monthly parental empowerment sessions were arranged 5 days in a week to engage the parents and improve their parenting skills in homes to provide a shared/group activity atmosphere.

At Term 4, COVID 19 pandemic and locked down became a main challenge. Therefore, virtual play sessions were conducted and parents were asked to update children's daily activities in the Whatsapp and Viber group.

End of the 4th term, the following reflections were given by parents:

Challenge 1- The parents don't have adequate internet coverage to provide the continuous care

Challenge 2- The child struggled to get familiar with virtual sessions and lost the gained behavioral change gradually

To overcome the challenges faced in the term 4, researchers empowered the parents over the phone calls and explained the purpose of doing the activities as continuously, individually and groupwise in proper way to develop the skills and to re-gain good behavioral change gradually in the children. Further family members were motivated to engage and involve actively to provide continuous care by using family members residing in respective nuclear and/or extended families.

Charting

The reflections of 5th term paved a way to create the implementation strategy to manage ASD. The parents or guardians were encouraged to update the outcome in whatsapp/ viber group. Sharing experiences whether good memories regard their children and or stressful moments regard them as well. A previous study of same area observed that this type of training helps the patients to have a more frequent and regular interactions with their care providers, and minimize the travel cost and improve their self-confidence in handling the children at their home¹⁴. The reflection was highlighted for the most appropriate child-centered plan with continuity in-person care and it was finalized the action plan and implementation strategy for managing ASD at the end of term 6.

Mapping and interpreting

Term 6 finalized the implementation strategy by mapping the participants and interpreting. Whole family approach is most suitable in low resource setting along with trained shadow teachers, expert's guidance to structure the play activities, human touch and routine clinic assessments were addressed as components of the developed implementation strategy.

Followings are the findings of this case study:

1. Action plan- Child centered plan with correct stimulus as group and individual play activities and continuity care for behavioral changes
2. Implementation mode- Whole Family approach with the support of trained shadow teachers

The strengths of the study were conducted in the local community by utilized the available resources with team work of the researched population which included specially trained shadow teachers and group activities for children. These sources facilitated socialization and automatically provide the atmosphere to develop self-care skills. Purposeful sampling technique¹² was used because of the limited resources and to collect rich and effective information. It might be a limitation.

Conclusion:

Structured child-centered individual and group play activities through whole family involved with the teamwork of trained shadow teachers and experts are the delivery mode of continuity care which is most suitable for the local context of Jaffna district, Northern part of Sri Lanka to enhance self-care and socialization among children with ASD.

CONFLICT OF INTEREST: There is no conflict of interest.

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