Case Study

Implementing community co-designed model to enhance functioning in autistic children through skill development play activities– A case study

Shanmuganathan Y [1], Kumaran S [1] and Sasrubi S[1]

Author's Affiliation:
1- Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna.

Correspondence:
Kumaran S, Email: s.kumaran3@gmail.com

Received on: 26-Apr-2023 Accepted for Publication: 25-Jun-2024

Continuity of care for autistic children is a significant challenge for care providers. Structured play activities are an evidence-based intervention for skill development among these children. An adaptive Collaborative Care Model (CCM) was implemented at the primary care level as a community-co-designed model to conduct evidence-based interventions with continuous follow-ups. The study was validated through periodical assessments of child growth milestones. The model enhanced independence, showing 82% improvement in gross motor skill development and 52% in pre-learning activities. In terms of life skill development, 35% of individuals still required guidance to perform tasks. The fidelity of the study demonstrated a 2:1 ratio of children to Community Health Workers (CHWs) in service delivery. The penetration of the study was highlighted by the continuous growth in the number of beneficiaries and the involvement of CHWs in service delivery. This model holds promise for not only Sri Lanka but also other countries in the region. By adapting the collaborative care approach to local contexts, other countries can similarly enhance the developmental outcomes of autistic children through structured play and continuous follow-up. The successful implementation and scalability of this model make it a viable solution for addressing the challenges in continuity of care for autistic children across the region.

Keywords: Implementation, Community health workers, Play therapy, Autism, Primary care

INTRODUCTION

Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain that affect socialization, self-care and learning of the child [1]. Symptoms can be observed from the age of 2 years, which include difficulty with communication and interaction with other people, restricted interests, and repetitive behaviors, as well as symptoms that affect their ability to function in school, work, and other areas of life.

In Sri Lanka, autism prevalence is at 1.07%, meaning it affects 1 in 93 children between 18 and 24 months. [2]. Among the identified children with special needs, 10.6% of them are in school-age, and only 0.4% attended schools or special education units [3]. While ASD is considered a lifelong disorder, an effective intervention can improve a child's functioning [4]. The play-based interventions with clinical reviews along with periodical assessments of growth milestones were evidenced as post-diagnostic management of ASD [5].

Continuity of care at the community level is a challenging task for the care providers because of social stigma, negative attitudes towards children with special need, poor economic status of the parents, and lack of trained human resources for service delivery [3]. A feasibility study was conducted to implement structured play activities by training selected community members as coaching assistants and empowering the parents of ASD children in Jaffna District, Northern Province, Sri Lanka from 2020 to 2022 and published [6].

The findings of the feasibility study facilitated the researchers to empower the women as trained CHWs [7] to implement continuity of care with clinical reviews and periodical assessment. Therefore, this study was developed with an implementation plan of community co-designed model for continuity care intervention for ASD children's skill development through structured play activities with trained CHWs, clinical reviews and periodical assessment in low-resource settings.

The aim of this study was to implement a community co-designed model for continuity care to enhance the skill development among autistic children.

Methodology:

The implementation study was carried out for a period of three years, from May 2020 to May 2023. The primary care with clinical set-up was selected as the study setting to achieve continuous follow-up, child-centered care and address various clinical observations of ASD children during the study period, such as stress, anxiety, attention deficit, hyperactivity, sleep, gastroenterology and nutritional needs. The sample selection was done through the referral system of primary care provider using snow ball sampling technique according to the child's medical condition. Children aged between 2 and 15 years and their parents/ primary caregivers were selected for the study.

There were four phases in the study: preliminaries, pre-implementation, implementation, and post-implementation. Each phase focused on certain implementation outcomes. Each of the major implementation steps was also considered a work package.

Phase 1: Preliminaries

The preliminaries phase was carried out for six months, from May to November 2020. This phase aimed to assess acceptability and adaptability among the core team members, stakeholders and target population. Two work packages included in this phase.

Work package 1: Preliminaries for implementation

Challenges in self-care, socialization and learning with autism and caregiving burden were reflected the need of implementing an evidence based community co-designed model at primary care level to provide appropriate and continuous care in clinical settings. Play therapy was selected as an evidence-based post-diagnostic management plan for children with ASD to enhance functioning skill development, which prevents or solves psychosocial difficulties and helps to achieve optimal child-healthy growth or development in behaviour, self-respect, socialization, expression of feeling or thoughts and learning from others. Play therapy is cost-effective and recommended to provide continuous sessions with organized child-centred individual plans [8].

CHWs were included into the continuous care plan to facilitate not only conducting regular session but also to empower the community to break negative attitude and social stigma towards special need children. Clinical

reviews and periodical assessments were planned according to World Health Organization' child growth milestone [9].

Work package 2: Preparation for implementation

The primary care provider (Consultant Family Physician) mapped school dropout girls aged above 18 years as the target group to train as CHWs for continuity care delivery. The plan was presented to convince stakeholders. Infrastructure facilities and physical space was arranged by Green Memorial Hospital. Friends of Manipay agreed to pay staff salaries. A behavioural change professional (Nutritionist) also joined the core team.

Phase 2: Pre-Implementation

The implementation phase was carried out for 18 months, from May 2020 to November 2021. This phase aimed to develop a feasible implantation plan and pilot it. There were two work packages in this phase.

Work package 3: Target group training

Six-month training program (May to November 2020) began with involvement and engagement activities. The core team hired resource persons from multiple disciplines for theoretical sessions for community health workers. Soft skills towards the final destination of the training were organized by the Core team with various exposures in a periodic manner, such as site visits, interaction with autistic children, and experience sharing by professionals and parents. Skills development and the challenges for an autistic child were addressed as a plan with appropriate play activities for gross motor skills, fine motor skills, sensory processing development, life skills for independence, communication, creative skills, visual and auditory skills for pre-learning and reading, writing and math for basic learning.

Work package 4: Feasibility study

The Feasibility study was carried out for 18 months from 2020 May to 2021 November (6). Structured child-centered individual and group play activities through parental empowerment with the assistance of trained CHWs and BCPs at primary care level was developed as the suitable service delivery mode of continuity care in the low resource setting of Jaffna District.

Phase 3: Implementation

The implementation phase was carried out for one year from December 2021 to November 2022. This phase aimed to implement the piloted plan with validation.

Work package 5: Fidelity study

According to the findings of the published feasibility study, the components of service delivery could be organized in a similar way to evidently proven Collaborative Care Model (CCM--figure 1) , which can be practised at primary care level contented stepwise measurable targets with clinical reviews (10). The formulated CCM was implemented with trained CHWs, behavioural change professional (BCP), and Consultant Family Physician (CFP) as the components of the service delivery triangle. Person-oriented medical records were

maintained for each child, and the overall general register was included in the registry. The roles of each components of developed CCM and the frequency of contacts were defined.

The children with autism were identified by the CFP during clinical practice and referred to the collaborative care model system. An assessment note of referral was received by the BCP. The detailed activity plan was developed by the BCP after the client orientation period. The activity plan was implemented by the trained CHWs. Two hours per day and six days in a week were allocated for structured play activities for each child. CHWs facilitated individual and group activities. The performance of the child was monitored by BCP in every session, and the individual plan was changed accordingly. Once in three months, the achievement of skill development was assessed by CFP.

Parents of the children were welcomed to gather information to be involved in everyday skill development activities with CHWs. Also, the parents were addressed by BCP regarding monthly goals in skill development and observations of their children during the structured play activities. Observation in the home and feedback of the parents were collected. Periodical parental empowerment sessions and individual meetings were conducted by CFP to update their understanding on child's development gaps and achievements.

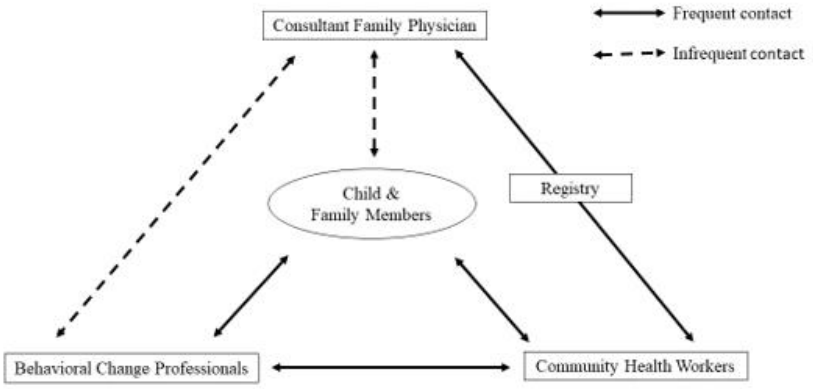

Figure 1: Components of collaborative care model

The steps of CCM were developed with measurable targets of child growth milestones [9]. An institutional based cross sectional descriptive study was carried out among seventeen children with Autism Spectrum Disorder in pediatric center, Green Memorial Hospital, Manipay, Sri Lanka to assess the status of motor domain, cognitive domain, life skill and pre-learning skill using a comprehensive tool developed according to literature review (Table 1). The activities were scored according the child's performance and then divided into number of items. The final score was predicted whether such particular skill need to be introduced/ with guidance the child can practice his own/ need to be modified/ need to be tuned fine [10].

Table 1: Assessment Tool

Scales/ Subscales	Examples of items	4	3	2	1	0
I.Fine motor domain						
1.Palm strength	Play with hand bell					
2.Finger grasp	Holding a pencil					
3.Manual dexterity	Play xylophone					
4.Fingertip sensation	Give ice cubes					
5.Reaching, manipulating, exploring	Reach the ring and hold and start to play					
6.Speeding up of fine motor activities	Put in coins into Till box					
II.Gross motor domain						
7.Head and neck control	Follow the commands					
8.Hand muscle movement	Follow the commands					
9.Strengthening the long muscles in hand and legs	Follow the commands					
10.Control of the long muscle's movement	Follow the commands					
11.Body balance	Instruct to stand still for 2 minutes					
III.Life skills						
12.Eye contact	Regards a person momentarily (count 3)					
13. Eye co-ordination	Hold the ring and moves horizontal, vertical, and circular movement.					
14..Listening the communication (Receptive Language)-.	He understands sentences of two familiar words in context					
15.Responding the communication (expressive Language)-	He can comment on his own actions					
16.Routine self- care activities	Brushing, bathing, clothing, etc					
17.Behavior in outside-	Be silence, walk together					
18.Celebrating special days	Birthday function					
IV.Creativity/ Cognitive						
19.Different shapes, colors, figures, scenarios	He can fit shapes, colors, figures, scenarios of different into each other					
20.Feel 3D dimension	Rectangular prism- book/ gift box, Sphere- Ball, cone- carrot/ ice cream					
21.Stimulation for thinking ability and imagination	Mends broken doll exactly					
22.Memory	Uncovers toy					
23.Understanding relationship	Discriminates people					
V.Pre-learning skills						
24.General talk	Vocalizes four different syllables					
25.Pencil control	Reaches pencil and attempt to write/ draw					
26.Differentiate odd-	He can fit objects of different object into each other					
27.Grouping similar objects-	He can fit objects of similar shapes					
28.Know numbers, letters	Says 1,23.. A,B,C… A.P.P.L.E.					
29.Able to understand and do simple math	Count Apples in two bags					
30.Able to do easy language practice- writing, listening, speaking, story telling	Listens selectively to familiar words and continue with task					

0- No need attention 1- Need to fine tune 2- Need further modifications
3- Need guidance 4- Need to introduce

The evidence-based practice implementation was validated through the tool's quantification scores.

Phase 4: Post-implementation

The post implementation phase aimed to study the penetration of service in the context for 6 months from December 2022 to May 2023. Coverage of service, client outcomes and involvement of CHWs and stakeholders were quantified.

Indicators for evaluation:

Outcome indictors were used to measure the key milestone in this study, which was developed by adapting Proctor et al, 2010 to measure Fidelity and penetration. Data were collected under the themes of outcome indicators.

Data collection and analysis

Routine clinical data was collected from the registry as quantitative data of implementation process. The scores of periodical assessments were considered as quantitative data of skill development activities for validating the implementation. Descriptive statistics was used to analyze the data.

Results:

Validation of implementation

The validity of the implementation was measured with the assessment tool. There were 17 children who participated in validation study. The majority (64.7%, n=11) were males. The mean age was 7.5 (±2.4) years. The scores of the dependent variables, viz., fine motor, gross motor, life skill, creativity/ cognitive, and pre-learning skill were measured. The result indicated that the majority (82.4%, n=14) of the children were found to perform well independently in gross motor, while only 17.6% (n=3) of the children didn't need help in fine motor activities. Life skills have to be developed with further modification (35.3%, n=6). Guidance needed in creativity assessment (70.6%, n=12) and pre-learning (52.9%, n=9) (11).

Fidelity of implementation

No changes were made to the adapted CCM model. , The ratio between the number of children under care and CHWs, was maintained as 2:1 throughout the implementation process after the feasibility study. The table 2 illustrate the growth of indicators for client, service and implementation outcomes.

Discussion:

In Sri Lanka population-based screening programmes for autism in SriLanka, and autism screening is not a mandatory partof primary health care [11]. In addition to such observation, a study carried out in Colombo district also reported that the inadequate skills of health professionals are one of the possible reasons for the delay diagnosis of Autism [12].

Table 2: Indicators of implementation

Indicators	2020 Jun	2020 Dec	2021 Jun	2021 Dec	2022 Jun	2022 Dec	2023 Jun
1. Client outcome							
Number of children	1	5	15	22	26	30	34
2. Service outcomes							
Number of days in a week for service delivery	3	3	3	5	5	6	7
Number of empowerment sessions conducted during 6 month periods	0	0	1	1	1	1	1
Number of clinical review days allocated for CFP in a week	2	2	2	2	2	2	2
Number of client allocated per clinical review day (30minutes per child)	2	2	2	2	2	2	2
Number of observation days allocated for BCP in a week	3	3	3	5	5	6	6
Number of recruited CHWs	5	7	8	10	10	11	11
Number of trainees as CHWs	0	0	2	2	3	3	3
3. Implementation outcomes							
Number of CHWs' salary paid by stakeholders	5	6	7	7	8	8	8
Ratio between children: CHWs	1:5	5:7	3:2	2:1	2:1	2:1	2:1

Our study aimed to implement CHW-facilitated structured play activities to enhance the skill development among children with ASD at the primary care level. A previous case study from this clinic also reported that it was obviously observed that whenever the child seems to be bored, parents were asked to join with various activities such as artwork, imaginary play, jump rope, catching or kicking the ball, reading, dancing, listening to music and setting up activity stations (e.g., book area, drawing area, physical activity area) [13].

According to Boyd et al (2010), co-design methods can be used to improve patient experiences and services within healthcare organisations through six step process as engage the benificeries by sharing the information about co design, plan feasible through communication, explore the influences and navigate, develop coordination plan with beneficerie's active participation, decide and change towards sustainability and emerged with current environment [14]. In this case study also the six step process were carriedout to form effective co designed model.

Results of the validation, fidelity and penetration indicators highlighted the efficiency and effectiveness of the implementation. Only convenience stakeholders participated in the feasibility study, which was already published, and continued for the fidelity study as well. Therefore, the contribution percentage as funders,

infrastructures and facilities providers couldn't be studied under adaptability, acceptability and adaptability indicators.

The research evidence reported strong relationship between treatment effectiveness and the inclusion of parents in the therapeutic process and maximum effect sizes occurring after approximately 30 treatment sessions [15], which was observed in the co designed model also.
Further, system development towards maintenance and sustainability can be suggested to incorporate parents as active participants along with CHWs to conduct the service delivery. Also, qualitative analysis of beneficiaries' satisfaction, empowerment status and sharing caregiver burden can be audited periodically to monitor the maintenance. An outside referral channel can be developed to expand the coverage.

This adapted CCM model can be implemented in other areas of Northern Province with special trained primary care provider, behavioral change professional and trained CHWs in low resource settings as a post diagnostic care delivery for ASD at primary care level. CHWs are the facilitating factors in this study because they could spread the positive attitude in the community towards special need children and their skill development to showcase independences future.

In addition to the study findings, the framework used for implementation and indicators used for evaluation were piloted. The findings of the study signified that the framework and indicators used were context specific as well as could be generalized. Therefore, they can be recommended as feasible materials for similar implementation studies. Further, developed CCM, defined the roles of involvers thus paved the way towards maintenance and sustainability of the system by creating standard operations procedures. Ultimately pre-test, posttest design may evaluate effectiveness of traditional play activities to build up self-care, socialization, and learning in children with autism. Further, to provide a comprehensive care to the child partnership should be developed with other institutions to handle the issues of limited resources in the primary care settings.

Conclusion: The developed Collaborative care model with community health workers, behavioral change professional and Consultant Family Physician is most suitable community co-design model to practice to enhance the functioning of ASD children through continuity care for skill development with structured play activities, clinical reviews and periodical assessment at primary care settings.

Conflict of interest: There is no conflict of interest among the core team, stake holders and beneficiaries.

Acknowledgement: The core team acknowledge the staff in Pediatric Neurodevelopment clinic, Green Memorial Hospital, Manipay, Friends of Manipay and Family Health Center, Kondavil for their support in this study. Participants of each levels were acknowledge for their contribution.

References:

1. Centers for Disease Control and Prevention. What is autism spectrum disorder? In Handbook of Parent-Child Interaction Therapy for Children on the Autism Spectrum, 2019; 3–26. https://doi.org/10.1007/978-3-030-03213-5_1
2. Rohanachandra YM, Dahanayake DMA, Rohanachandra LT, Wijetunge GS. Knowledge about diagnosticfeatures and comorbidities of childhood autism among doctors in a tertiary care hospital.Sri Lanka Journal ofChild Health 2017; 46(1): 29-32 (http://doi.org/10.4038/sljch.v46i1.8093)
3. Muttiah, Nimisha , Kathryn, Drager & O'Connor, Lindsay. Special Education in Sri Lanka: A snapshot of three provinces. Disability Studies Quarterly.2016;36: 10.18061/dsq.v36i2.4388.
4. American Psychiatric Association (2023)a. Available at; https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder
5. Hyman SL, Levy SE, Myers SM; Council on children with disabilities, section on developmental and behavioral pediatrics. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020;145(1):e20193447. doi: 10.1542/peds.2019-3447. Epub 2019 Dec 16. PMID: 31843864.
6. Kumaran. S, Shanmuganathan. Y and Sasrubi S, Community co designed Model – Enhancing self-care and socialization of children with Autism Spectrum Disorder in Northern Province, Sri Lanka, Asia Pac J Paediatr Child Health, 2022(5):36-40.
7. Shanmuganathan Y, Raguraman S, Kumaran S, Shiribavan K. Women empowerment is a tool to improve the quality of life of a community-case study. Jaffna Medical Journal. 2023;35(1):10-14. DOI: https://doi.org/10.4038/jmj.v35i1.178
8. Elbeltagi, R., Al-Beltagi, M., Saeed, N. K., & Alhawamdeh, R. (2023). Play therapy in children with autism: Its role, implications, and limitations. *World journal of clinical pediatrics*, *2012*(1), 1–22. https://doi.org/10.5409/wjcp.v12.i1.1
9. World Health Organization (2023), Child growth standards. Available at: https://www.who.int/tools/child-growth-standards
10. Sasrubi S, Kumaran. S and Shanmuganathan. Y, Play-based interventions to assess motor domain, cognitive domain, life skill and pre-learning skill in children with autism of Jaffna district, Sri Lanka, Proceedings of the International Conference on Medical Sciences (ICM) 2023, Faculty of Medical Sciences, University of Sri Jayewardenepura, pp: 149
11. Surenthirakumaran R, Kumaran S, Sasrubi S. Case study of the management of a child with Autism Spectrum Disorder (ASD) – Northern Province, Sri Lanka. Sri Lankan Family Physician. 2021; 36 (1): 79- 81
12. Pfeiffer BA, Koenig K, Kinnealey M, Sheppard M, Henderson L. Effectiveness of sensory integrationinterventions in children with autism spectrum disorders: a pilot study. Am J OccupTher. 2011;65(1):76-85. doi:10.5014/ajot.2011.09205
13. Surenthirakumaran R, Sasrubi, S. The management of a child with Attention Deficit Hyperactivity Disorder during COVID-19 lock down in Northern Sri Lanka. Asia Pacific Journal of Paediatric and Child Health.2021; 4: 52-54.
14. Boyd H, McKernon S, Mullin B, Old A. Improving healthcare through the use of co-design. N Z Med J. 2012;125(1357):76-87. PMID: 22854362.
15. Leblanc M, Martin R. A meta-analysis of play therapy outcomes. Counselling Psychology Quarterly. 2001; 14: 149-163. 10.1080/09515070110059142.