

Initiation of Sustainable Community Co-Designed Model for Children with Neurodevelopmental delay - Case Study

Shanmuganathan Y¹, Kajana MC², Suthargene R³, Tamilcelvi S⁴, Thivakar K⁵, Thayalini B⁶, Sasrubi S⁷, Thurga J⁸ and Kumaran S⁹

¹Masters in Food and Nutritional sciences, Registered Dietitian and Nutritionist, Research fellow, Center of Digital Epidemiology, Faculty of Medicine, University of Jaffna, Sri Lanka

²Bachelor of Siddha Medicine and Surgery, Diploma in Counselling and psychology, Family Health Center, Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka

³Bachelor of Dental therapy and Oral hygiene, Family Health Center, Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka

⁴Research fellow, Center of Digital Epidemiology, Faculty of Medicine, University of Jaffna, Sri Lanka

⁵Ayurvedic Medical Officer, Department of Ayurveda, Ministry of Indigenous Medicine, Sri Lanka

⁶Unani Medical Officer, Department of Ayurveda, Ministry of Indigenous Medicine, Sri Lanka

⁷Nursing officer, Research assistant, Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka

⁸Research fellow, Teaching hospital, Jaffna, Sri Lanka

⁹Consultant Family Physician, Head, Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna

*Corresponding author

Subachandran Kumaran, Consultant Family Physician, Head, Department of Community and Family Medicine, Faculty of Medicine, University of Jaffna, Sri Lanka.

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ABSTRACT

This six-year study (2019–2025) presents a community co-design model using participatory action research (PAR), guided by CFIR and the COM-B framework to examine organizational and individual behavioral change. Across three phases—Feasibility, Fidelity, and Sustainability—staff, parents, and children engaged in structured interventions. Staff gained skills in child-centered care and event coordination, parents enhanced emotional management and home-based support, and children developed motor, social, and problem-solving abilities through play, thematic sessions, and individualized interactions. The interplay of opportunities, motivation, and capability fostered skill development, empowered parents, strengthened staff competencies, and demonstrated the feasibility and sustainability of the model in resource-limited settings.

Keywords: Community Co-Design, Neurodevelopmental Delay, Participatory Action Research, Com-B Model, Implementation and Sustainability

Introduction

The alarming prevalence of neurodevelopmental delays among children creates fear and uncertainty among parents, who often struggle to envision a future for a child dependent on others for daily living activities, limited socialization, and learning difficulties [1]. In response, many parents are willing to spend

substantial amounts of money to address these challenges. However, in a lower-middle-income country like Sri Lanka, balancing the economic needs of the family while seeking specialized care is a significant challenge. This situation increases the caregiving burden and negatively affects parents' physical, mental, and social well-being, often leaving them unable to care for themselves or other family members [2].

This vicious cycle disrupts family dynamics, places overwhelming stress on the primary caregiver, and extends its impact to other

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family members and even the younger generation [3]. In response to this pressing need, a sustainable community co-design model was initiated to support children with neurodevelopmental delays throughout their life course [4,5].

The Pediatric Neurodevelopment Clinic was established in 2019 at Green Memorial Hospital, Manipay, in the Jaffna District of the Northern Province, Sri Lanka [6]. It was initiated as a community co-design model to provide post-diagnostic management plans and support skill development among children with neurodevelopmental delay through structured play activities [7]. The clinic has been running for over five years with the vision of fostering children's skill development through structured play-based activities, alleviating caregiver burden of parents, and empowering young female school dropouts by engaging them as coaching assistants. These services are provided free of charge and are supported by Friends of Manipay Hospital, a non-governmental organization that funds for staff salaries and capacity-building programs [6].

Objective

The study aimed to showcase the key components of the community co-design model and highlighting its sustainable initiatives over the past six years.

Methodology

The study period spanned from 2019 to 2025 and employed participatory action research (PAR) methodology to develop the

community co-design model [8]. All registered children, parents, staff, and stakeholders were included as study participants. The implementation process was guided by the Consolidated Framework for Implementation Research (CFIR) as an evidence-based framework, alongside the COM-B model to analyze institutional behavioral development through participatory action [9,10]. The use of CFIR provided a structured approach to understanding implementation at the organizational and system level, while COM-B complemented this by addressing behavioral change at the individual and institutional level.

The study was structured into three major phases, aligned with CFIR: Phase 1 – Feasibility work (2019–2021), Phase 2 – Fidelity assessment (2022–2023), and Phase 3 – Sustainability initiation (2024 onwards). At each phase, reflections on participants' actions were collected as qualitative data from all levels of participants and analyzed according to the COM-B model dimensions of capability, opportunity, and motivation.

Results and Discussion

The COM-B framework was employed to examine motivation, opportunity, and capability among staff, parents, and children. Findings indicate that the opportunities provided not only enhanced participants' motivation but also positively influenced the development of their capabilities throughout each phase.

Table 1: Results of COM B model assessment of shifts in institutional culture and behaviors

	Given opportunities	Motivation	Developed capabilities
Phase 1			
Staff	On the job training	Social recognition for school dropout females	Skilled to care the children through structured play
Parents	Evening sessions (also accessible to school-going children)	Free services for local	Skilled in providing straightforward reflections and inviting requests of services.
Children	Appropriate stimulations and exposures through play	Joy in playing	Skill development in gross motor, fine motor, eye contact, life skills, patience, turn taking and group work
Phase 2			
Staff	Extended working hours were complemented by the additional opportunity to serve as a shadow teaching assistant within schools as well.	Promoting economic attainment among school dropout females, enabling them to contribute to the support of their families	Demonstrated expertise in child-centered care and in supporting educational and learning activities
Parents	Conducted regular empowerment sessions aimed at enhancing parents' understanding of their children and support for learning difficulties through shadow teaching assistants	Developed motivation for effective emotional management through shared caregiving responsibilities	Enhanced parents' or caregivers' abilities to integrate a child-centered management plan into daily home routines
Children	Organized monthly thematic sessions culminating in skill exhibition events	Prevented participant fatigue by introducing variety in activities	Developed the ability to trial new regulations

Phase 3			
Staff	Offered targeted learning opportunities such as pre-learning, communication and language development	Motivated to specialize in each developmental domain	The supervisors' caseload decreased as staff took on greater responsibility and effectively coordinated the monthly events.
Parents	Opportunities were created for parents to engage with multidisciplinary teams in developing and implementing their children's management plans.	Engaged with doing and learning the management plans with staff	Skilled to support the staff to reduce caseload in child centered care activities.
Children	One-to-one interactions were focused on specific skills along with socialization opportunities.	Interactive interactions and choice makings promoted to be engaged	Children gradually began exhibiting the ability to initiate actions fearlessly and build confidence in problem-solving, enabling them to express themselves assertively without aggressiveness or withdrawal

Phase 1

Among staff, social recognition was the primary motivator, while opportunities for on-the-job training supported capacity building. Parents were motivated by free service delivery within the local community, and post-school scheduling enabled participation without disrupting daily routines. Providing space for straightforward reflections and open requests further strengthened parental engagement. For children, play acted as the main motivator, and structured stimulation and exposure supported skill development. Collectively, these factors enhanced children's overall proficiencies.

Phase 1 demonstrated that child-centered, structured play activities, supported by shadow teaching assistants, were feasible even in resource-limited settings, despite challenges such as the COVID-19 pandemic and economic crisis. The presence of a clinical coordinator with strong problem-solving skills and comprehensive assessments by a consultant family physician at entry further enhanced feasibility. Service delivery initially ran for two hours, three days per week, later expanding to five days per week.

Phase 2

Staff motivation in Phase 2 was primarily driven by economic opportunities for female school dropouts. Extended working hours and shadow teaching assistant roles enhanced their skills in child-centered care. For parents, sharing caregiving responsibilities reduced pressure and increased motivation, while program participation empowered them to support children's development at home. Children were motivated by monthly themes, and structured stimulation provided opportunities to demonstrate skill development during monthly events.

Children attended sessions with community health workers (CHWs) six days per week and periodically met family physicians and behavioral change professionals. Multi-disciplinary input from a nursing officer and nutritionist informed comprehensive assessments. A 1:2 CHW-to-child ratio ensured individualized attention, and shadow teaching for school-going children enhanced both child and parent confidence. Children with neurodevelopmental delays who had migrated were included during school vacations to maintain continuity of care.

Phase 3

Staff motivation increased through promotions to activity-based roles, while expanded learning opportunities strengthened their capabilities via planning and coordinating monthly events. Parents were motivated by children's achievements and engaged in supportive roles, informed by multidisciplinary team feedback. A comprehensive team—including nursing, nutrition, counseling, dental therapy, physiotherapy, preschool teaching, fine arts, and gardening specialists—enhanced service comprehensiveness and continuity. Targeted staff capacity building, especially in speech and language coaching, addressed service gaps. Active parental involvement facilitated daily provision of nutritious snacks and helped manage case overloads. Individualized interactive sessions for children fostered capabilities, demonstrated through fearless initiation and problem-solving skills.

Sustainability and Outcomes

Positive outcomes from the first two phases and concerns about children's long-term development prompted sustainability measures such as parents' active involvement along with expertness of staff in each developmental domain. A hospital gardening area was transformed into a learning garden to foster independence among the children's skills development. Revenue from garden harvests, combined with service charges from migrated children, provides vocational support and contributes to financial sustainability. Currently, 12 staff members serve a maximum childcare capacity of 24 children, with 56 beneficiaries registered. The service has been permanently integrated into the hospital structure.

Conclusion

The pediatric neurodevelopment clinic at Green Memorial Hospital, Manipal, demonstrates how a community co-design model can offer sustainable, context-appropriate solutions in a low-resource setting. Over six years, the phased implementation journey, guided by participatory action research, CFIR, and the COM-B model—illustrated feasibility, fidelity, and sustainability in delivering child-centered, multidisciplinary care. The integration of parents, school dropouts, health professionals, and stakeholders fostered shared ownership, reduced caregiver burden, and promoted skill development and

independence among children with neurodevelopmental delays. Embedding the service within the hospital structure, supported by innovative approaches such as vocational gardening and partial cost-recovery, ensured continuity and financial resilience. This model not only addresses immediate developmental needs but also provides a replicable pathway for long-term, holistic care of vulnerable children in similar low- and middle-income country contexts.

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