

Establishing a novel partnership model to deploy health services for children with autism in a low-resource setting – experience from Sri Lanka



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Summary

Sri Lanka is representative of challenges faced by low-income and middle-income countries, including the rise in the prevalence of autism and the lack of sufficient autism-specific services in the state sectors. The experience in establishing a Center to provide services for children with autism in Northern Sri Lanka is described. Funding and resourcing were accessed through an innovative partnership-based public/non-governmental organisation/charity model, where service-based outcomes were the main objectives. This model, incorporating state institutions, local and international charity organisations, and volunteers, devised a bespoke approach to care provision using the available resources under the clinical supervision of a consultant psychiatrist and the administrative purview of the Regional Director of Health Services. The evolution of this Center into a Learning Health System is described, reflecting how a minimalistic partnership approach focused on the integration of existing organisations and services could be a feasible model for the delivery of high-quality healthcare in low-resource settings.

The Lancet Regional Health - Southeast Asia 2023;17: 100255

Published Online 28 July 2023

<https://doi.org/10.1016/j.lansea.2023.100255>

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Keywords: Autism; Low resource setting; Viewpoint; Sri Lanka

Introduction

The global prevalence of autism has steadily increased over the past decade from an estimated 62 per 10,000 (0.62%)¹ to estimates of 1% as reported by the WHO² and more than 2% as reported by the Center for Disease Control and Prevention.³ This rise in the prevalence of autism is seen both in high-income countries (HICs) as well as low-income and middle-income countries (LMICs), including within South Asia.^{4,5}

Sri Lanka, an island nation in the Indian Ocean with a population of 22 million, has achieved health indices comparable to western part of the globe, including infant mortality rate, maternal mortality rate, immunisation coverage, and life expectancy.⁶ Although the country has a well-organised primary healthcare system⁷ and has adequately managed conventional health problems, limitations in services for emerging health priorities, including neurodevelopmental disorders, have been exposed. Northern Sri Lanka, around 400 km from the country capital Colombo, has a population of 1.2 million, predominantly with a Tamil-speaking ethnic identity. This Viewpoint endeavours to share the learnings from establishing an Autism Center in northern Sri Lanka, which could be of use in pioneering services

for emerging health priorities in other low-resource settings.

Autism in Sri Lanka

In 2009, a Sri Lankan study⁸ found that 1.07% of children (1 in 93) aged 18–24 months were diagnosed with autism. Although there is a paucity of studies to assess the changes in prevalence, the general consensus amongst clinicians points towards a rise in the incidence of autism in Sri Lanka.

The increased awareness of autism over the past decade has extended beyond healthcare practitioners and educationists to involve the wider public. This has created unprecedented demand on the limited services available in the health and education sectors. Only a handful of child psychiatrists and even fewer clinical psychologists are available in Sri Lanka, mainly around the country capital, an unfortunate human resource scenario reflective of many LMICs. Hence, there is a great need to develop autism services within the wider state health sector, especially in regions distant from the country capital.

The case for deploying an Autism Center in Northern Sri Lanka

Northern Sri Lanka has gone through a “perfect storm” of several calamities over many decades, which has

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created additional burdens on the provision of health-care services in the region. These include a three-decade-long armed conflict, the resultant brain drains, several natural disasters (especially the tsunami in 2004), and ongoing political and economic challenges. Although recovering slowly, the northern region is reflective of challenges and demands encountered by autism services in many low-resource settings, with the availability of only a couple of adult psychiatrists and general paediatricians and a paucity of child psychiatrists, developmental paediatricians, clinical psychologists, and allied health professionals. Although the special-needs education division of the Department of Education and a few other private and non-governmental organisations (NGOs) provide some useful services, they fall short of the standards required of an evidence-based practice. Hence, as in many low-resource settings, the majority of children with autism and other learning difficulties end up being marginalised from the main educational stream and deprived of specialised help. This has resulted in untoward suffering for the parents,⁹ having no access to any specialised support or educational services for their children. To address this need, an Autism Center was established in 2014 under the name “*Mathavam*” which, in the local language Tamil, means “great penance”.

Establishment of the Autism Center

Selection of a partnership model

In the aftermath of the 2004 tsunami, awareness of the mental health and psychosocial needs within Sri Lanka led to the formulation of the country's first mental health policy¹⁰ and the nationwide deployment of a range of district-based decentralised mental health services. Jaffna, a densely populated district in the Northern Province, also embarked on many new mental health services, commencing as partnerships between governmental organisations and NGOs which were gradually absorbed into the state health system over a period of time. The primary motivation to move towards a partnership model was the lack of financial and human resources within the existing state sector. The experience and successful outcome allowed the application of the same model for the establishment of the Center. Although the use of public-private partnership models is common in the health sector, especially in HICs,¹¹ we felt a public-NGO/charity sector partnership model was more appropriate for LMICs where service-based outcomes rather than investment returns remain the key driver.

Governance structure & funding model

This partnership model incorporated the Regional Directorate of Health Services (RDHS) of the Department of Health, the Faculty of Medicine of the University of Jaffna, the Mental Health Society (MHS) – a

mental health-based local charity, the International Medical Health Organization (IMHO) – a US-based charity, and the “*Manitha Neyam*” Trust (MNT) – a UK-based charity. The international dimension of the model was essential to ensure the sustainability of the funding process, given national economic uncertainties, and the potential for utilising overseas and diaspora resources.

A simple and flexible governance structure was established under the administrative umbrella of the RDHS, with an experienced adult psychiatrist overseeing the day-to-day management of the Center, and an advisory body consisting of technical experts, administrators, staff members, and parents providing overall technical guidance. Fig. 1 shows the organisational structure of the Center.

Addressing the initial challenges

The absence of any trained personnel and the urgent need to establish the Center necessitated an initial minimalistic approach. A graduate with a background in social work was recruited and trained as a therapist at the Child and Adolescent Psychiatric Unit, Christian Medical College Vellore (CMC), India, a renowned regional center providing services for children with autism. A part-time therapy assistant from the local health staff and a helper to provide general assistance were also recruited. Refresher training on interventional strategies was provided to both the therapist and therapy assistant at CMC.

The Center experienced the following initial challenges, which led to poor morale of the staff and a failure to meet the expectations of parents.

- An inadequate service model consisting of goal-oriented activities carried out solely by the parents based on a basic assessment tool – the Childhood Autism Rating Scale (CARS)
- The inexperience of the therapists and inadequate supervision by the psychiatrist and paediatrician, partly driven by the remote location of the Centre

The governance committee initiated changes to make the Center more effective, leading to an increase in specialized and general resources, introduction of a more elaborate system of documentation, and regular staff and advisory board meetings to monitor and surface issues for resolution. The Center was also relocated to a location with better accessibility. Experts from overseas were involved to facilitate in-depth discussions and training programs. Applied Behavior Analysis (ABA), an evidence-based system facilitating the effective treatment for autism,¹² was introduced, revising the therapy model followed at the Center to incorporate more hands-on intervention from therapists. This highlights the role diaspora resources could play in the success of similar centers in low-resource settings.

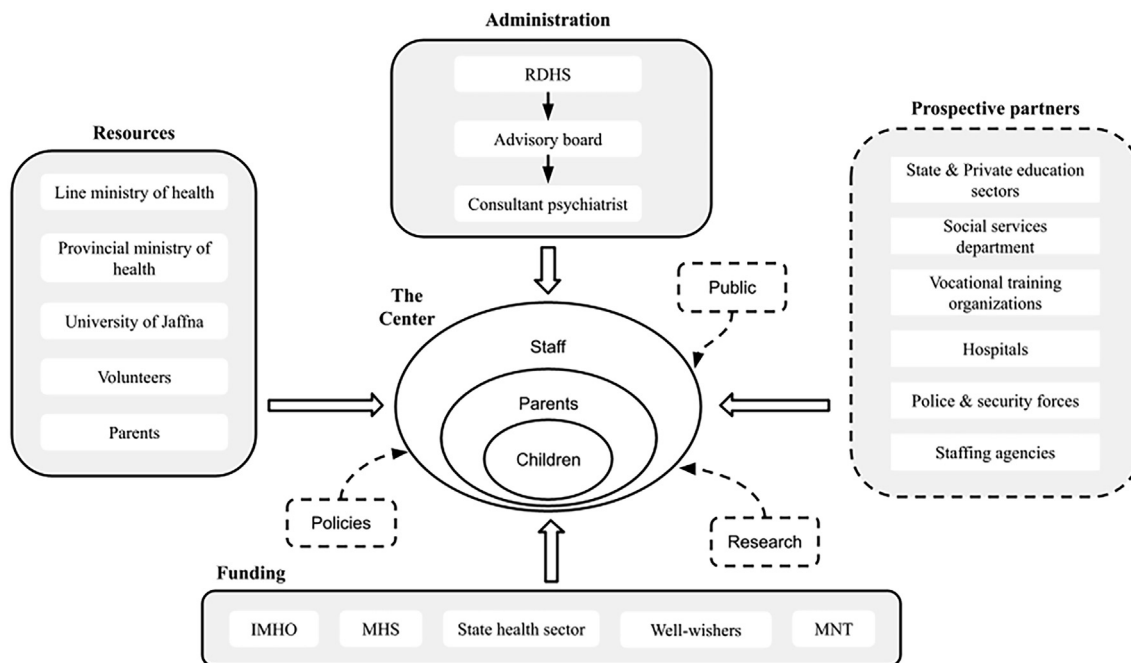


Fig. 1: The organisational structure of the Autism Center. IMHO, International Medical Health Organization; MHS, Mental Health Society; MNT, “Manitha Neyam” Trust; RDHS, Regional Directorate of Health Services.

Redesigning as a learning health system (LHS)

The rejuvenation of the Center paved the way for it to be restructured into an LHS to provide optimal care in a low-resource setting.¹³ An LHS is defined by the National Academy of Medicine as “a system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families as active participants in all elements, and new knowledge is captured as an integral by-product of the care experience”.¹⁴ It includes a group of people united by the common goal of addressing a particular health problem.¹⁵ The LHS at the Center is currently characterised by the presence of a diverse learning community, a well-organised documentation process, and a determination to improve services by the application of new knowledge created through audits and research.

Current status

From its inception in April 2014 to December 2022, the Center has provided services to 487 children (334 boys, 153 girls), including 336 with a diagnosis of autism, and currently has full occupancy. The Center is staffed by a set of full-time staff, including a medical officer trained in psychiatry and ABA-based behavioural interventions, four specialised therapists (behavioural and speech and language therapies), and four supporting staff. Part-time and flexible resourcing, including the use of parents as

co-therapists and volunteers from the community, remains a critical resourcing strategy. All staff undergo regular peer group and technical supervision, and virtual and in-person training. The partnership with regional health institutions allows access to shared services encompassing paediatrics, psychiatry, speech, and occupational therapies.

Care pathway for autism

The care pathway for autism in a well-resourced region normally includes a wide array of staff including general practitioners, child and adolescent mental health specialists, paediatricians, speech and language therapists, occupational therapists, physiotherapists, teachers, educational psychologists, learning support officers, and emotional literacy support assistants.¹⁶ However, in a low-resource setting, the challenge is to efficiently organise care pathways utilising the available resources. The care pathway followed at the Center is illustrated in Fig. 2.

In an environment of limited resources, care pathways need to be simple, flexible, and focused on maximizing the limited resources and enhancing patient interactions. Some simple practices instituted to meet these objectives are detailed below.

- Before the commencement of interventions, parents attend regular parental education programs that provide information on various treatment strategies

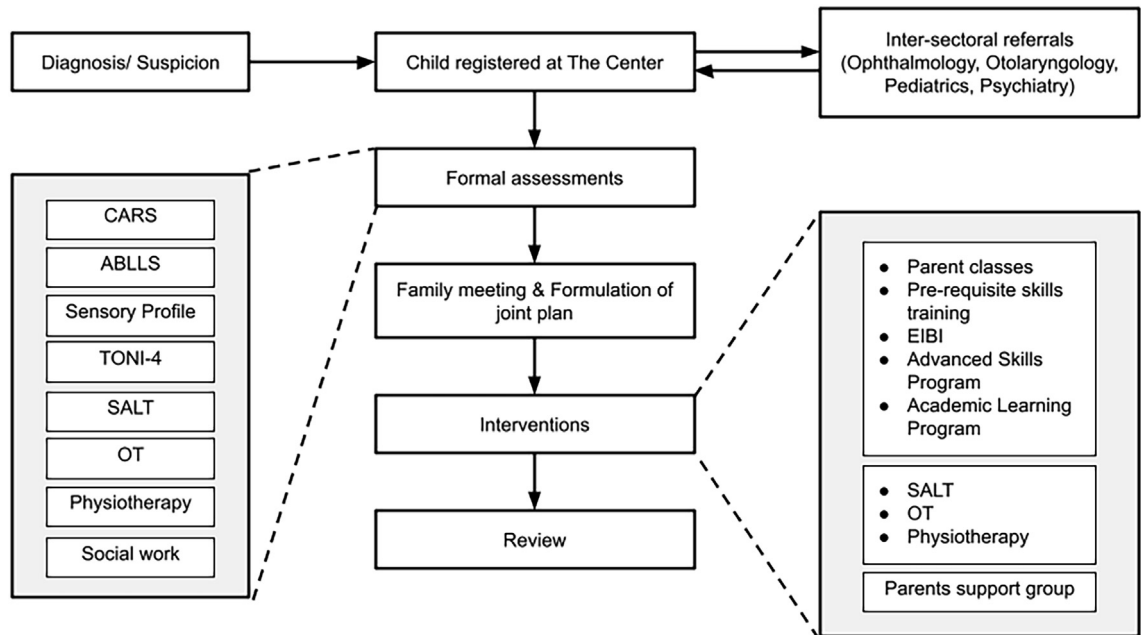


Fig. 2: Care pathway for autism followed at the Autism Center. ABLLS, Assessment of Basic Language and Learning Skills; CARS, Childhood Autism Rating Scale; EIBI, Early Intensive Behavioral Intervention; OT, Occupational Therapy; SALT, Speech and Language Therapy; TONI-4, Test of Nonverbal Intelligence - Fourth edition.

to improve essential motor, fine motor, imitative, cognitive, behavioural, and communicative skills, as well as parenting and relaxation techniques.

- During the waiting period for enrolment a therapist-guided parent-driven program is conducted for children to develop some basic prerequisite skills that were found to make Early Intensive Behavioral Intervention (EIBI) more effective. This program is mostly home-based, with a few sessions conducted at the Center.
- Interventions are tailor-made to the child's needs. EIBI, which remains the cornerstone of the program, is usually delivered by a therapist to one client at a time over several years at an intensity of 20–40 h per week.¹⁷ However, the involvement of parents as co-therapists, a hallmark in all processes at the Center, allowed the therapist-driven EIBI to be limited for three months followed by the continuation of therapy by the parents over the longer duration. For older children who have completed EIBI, an Advanced Skills Program and Academic Learning Program, which are based on learning in a classroom-like learning space, are conducted in the evenings, at a diaspora-funded adolescent therapy area.
- A bespoke and interconnected program of non-behavioural interventions is instituted through a multi-professional approach that paves the way for evidence-based and effective intervention strategies.¹⁸ These include,

- speech therapy, using Picture Exchange Communication System¹⁹ and a communication app, *Avaz*, to address specific speech-related challenges.¹²
- occupational therapy to promote functional independence²⁰ and address sensory issues.²¹
- physiotherapy to manage difficulties in motor movements,²² low muscle tone, and developmental coordination disorder,¹² and to realize improvements in communication skills often seen with improvements in motor control.²³

Other services

Although autism is the primary focus of the Center, children with other neurodevelopmental conditions, including global developmental delay, learning disability, and attention deficit hyperactivity disorder also approach the Center. In addition to the direct patient-centric services, the Center functions as a hub for continuous awareness campaigns, through the dissemination of knowledge via interviews, social media, and publications, and organising 'autism awareness days'. The Center also functions as a "training hub" for other stakeholders including trainers, teachers, and other service providers, and has developed networks with similar services locally, nationally, and internationally.

Enhancement of a data-based approach

The documentation system at the Center maintains a file for each child with details of assessments, therapy

goals, interventions, and communications with specialists and parents. Attendance at parent classes and feedback from parents are also logged.

Data analysis is conducted periodically to generate information. Records of individual children currently attending therapy are analysed weekly, assessing progress, inherent challenges, and areas for improvement. The multidisciplinary team explores the merits and shortcomings of ongoing programs at monthly meetings, whilst the advisory board meets quarterly to discuss organisational and therapy-related matters.

An evidence-based approach is further supplemented through studies conducted at the Center. Our previous study on parents to assess the perceived stress and coping mechanisms²⁴ led to improvements in the existing parent-support group. An audit between 2017 and 2020 assessed the clinical and sociodemographic characteristics of the children²¹ and facilitated an improvement in the diagnosis of autism by alerting the clinicians to the common presentations of autism in the context of local cultural and educational factors.

Striving forward

Measures of success

Mathavam is the main center providing services for children with autism in northern Sri Lanka. The large number of children who have benefited over the eight-year period, the increasing awareness of the Center's services at the national and international levels, and the consequential offer of continued support and funding, have been the obvious measures of success of the partnership model.

In a low-resource setting, volunteers are an important supplementary resource to maintain the services of any healthcare organisation.²⁵ The proximity of the Center to the University of Jaffna has resulted in a preponderance of student volunteers helping in producing photographic documentation of the Center's activities, facilitating autism awareness campaigns, and preparing materials for intervention programs. Involvement of undergraduates in societal activities is also critical for their own personal and professional development, and to create a more compassionate society. Volunteering has also been a feature amongst overseas visitors, who generously provide their expertise, time, and financial support.

Another critical and rewarding measure of success is how the activities of the Center led to an increased awareness of autism, paving the way for the development of a "Policy for Autism Management" in Northern Province.²⁶ A draft policy was established as a joint cross-functional venture between the health, education, and social service sectors, and was launched by the Provincial Chief Minister, ensuring high-level political commitment. This draft will be useful in the preparation of a National Policy, indicating how innovative

initiatives from decentralized regions can play an influential role in shaping national policies.

Current challenges and lessons learned

The major challenge encountered by the Center is the restricted availability of trained human resources and a low staff-to-children ratio, exacerbated by staff turnover due to the current political and economic situation in the country. This has resulted in a long waiting list to access the services, and the need to limit the number of children receiving EIBI and follow-up services.

Newly recruited staff have little experience or prior knowledge about children with autism. Most therapy-related national undergraduate curricula have only a limited exposure to autism. The Center will benefit from the launch of wide-ranging and structured training programs and the deployment of therapists with a career focus on neurodevelopment-related disorders.

The coordinated and integrated functioning of a multidisciplinary team is critical in low resource settings to enhance productivity. More work is needed to enhance cross-functional leadership skills. Another prominent challenge is the lack of assessment and therapy materials translated and validated in the local language.

Management of autism requires parents or caregivers to work in partnership with the children for many years. However, most parents expect a "quick fix" and managing their pressure has been challenging, with sporadic occurrences of untoward negative emotions towards the therapists as well as the Center itself. Allocating a designated staff member to specifically engage with and empower the parents is a priority.

Although services provided at the Center are free of charge, additional economic burdens are borne by the families for transport, purchasing training materials, and the interruption of regular work. These become counterproductive for the care of the child and remain the most pressing cause for therapy defaulters. The Centre has been exploring novel ways of linking families from low socioeconomic status with donor organisations.

The experiences gained from establishing and running this institution have imparted a key lesson: in a low resource setting, an institution established as a partnership-based learning health system is best equipped to provide efficient service delivery. Systematic gathering and analysis of data have enabled improvements in the outcomes of individual children, evidence-based decision making, knowledge and performance of therapists, and provision of value-based care. The inclusion of the family as part of the learning team is seen by the clients as a positive experience. Furthermore, the value of regular consultations with experts based overseas has ensured that the Center remains updated on therapy modalities and novel techniques. Another

important take-home message is the challenge of preparing for the inevitable increase in the demand for services brought about by the success of the Center in increasing awareness of autism.

Future directions

The Center should ensure its sustainability and enhance multiple partnerships to continue providing its invaluable services to the community.

Ensuring sustainability

Although the current partnership model has succeeded in providing the services at a critical juncture, its long-term sustainability is dependent on the eventual integration of the Center into the structure of the state sector. Continuous interaction and advocacy with all the relevant stakeholders and the demonstration of the beneficial outcomes at the Center will be needed to ensure this transition.

Enhancing partnerships

In LMICs like Sri Lanka, many ministries, departments, and services function in silos. A paradigm shift in mindset is needed to blur the organisational boundaries and achieve a collaborative venture. Although autism has been included in the special-needs education system of Sri Lanka in 2005,²⁷ it is only being implemented in a limited number of schools, reflecting a need for significant reforms in the education sector as well. Developing a future partnership between the Center and the state education sector will lead to the beneficial provision of long-term services and educational opportunities for children with autism.

Although the Center is now linked with undergraduate medical education at the University of Jaffna, extending this link to other allied health and education systems will help strengthen the training of therapists, and attract more community volunteers.

Conclusion

A public-NGO/charity partnership is an effective model for establishing services for emerging health priorities in settings with limited financial and human resources. Designing the initiative as an LHS enables the maximal utilisation of limited resources and improves the productivity and quality of services. Involving the parents and volunteers as additional resources provides a sense of ownership to the service users, their families, and the community at large. Finally, a minimalistic partnership approach focused on the integration of existing organisations and services could be a feasible model for the delivery of high-quality healthcare in low-resource settings.

Contributors

BS: Writing - Original Draft, Visualisation. **SS:** Conceptualisation, Writing - Review and Editing. **TK:** Conceptualisation, Writing - Review

and Editing. **GS:** Writing - Review and Editing. **NS:** Conceptualisation, Supervision, Writing - Review and Editing.

Declaration of interests

None.

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