

Needs Analysis for Developing a Parent-Mediated Naturalistic Developmental Behavioural Intervention Training Model for Parents of Autistic Children in Malaysia

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Abstract: Autism Spectrum Disorder (ASD) exhibits diverse developmental and behavioural challenges that require structured and consistent interventions. However, in Malaysia's low-resource areas, parents of autistic children often face limited access to professional support, high therapy costs, and geographical barriers that impede timely and effective intervention. Recognising parents as primary intervention agents in their autistic children's learning and development, this study aimed to examine the needs of parents of autistic children to design and develop a Parent-Mediated Naturalistic Developmental Behavioural Intervention (NDBI) Training Model. Guided by the Design and Development Research (DDR) approach, Phase I Needs Analysis employed a comprehensive literature review and individual semi-structured qualitative interviews with five parents of autistic children. Thematic analysis findings indicated Theme 1: lack of knowledge and limited access to behavioural intervention; Theme 2: parents as primary intervention agent in low-resource areas; and Theme 3: need for parent education and skills training in behavioural intervention. Therefore, parents showed strong desire for structured education and training. The Parent-Mediated NDBI Training Model provides a structured and dynamic reference framework for parents of autistic children to implement evidence-based developmental and behavioural strategies within natural daily routines at home. The training model holds significant implications for advancing parent education, enhancing early intervention accessibility, and guiding policymakers in promoting equitable autism services across Malaysia's diverse socio-economic and geographical contexts.

Keywords: Needs analysis, Parent-mediated intervention, Naturalistic developmental behavioural intervention, Autistic children, Early intervention.

Abstrak: Gangguan Spektrum Autisme (Autism Spectrum Disorder/ASD) menunjukkan beragam tantangan perkembangan dan perilaku yang memerlukan intervensi yang terstruktur dan konsisten. Namun, di wilayah Malaysia dengan sumber daya terbatas, orang tua anak autistik sering menghadapi keterbatasan akses terhadap dukungan profesional, tingginya biaya terapi, serta hambatan geografis yang menghalangi pelaksanaan intervensi yang tepat waktu dan efektif. Dengan menempatkan orang tua sebagai agen intervensi utama dalam pembelajaran dan perkembangan anak autistik, penelitian ini bertujuan untuk mengkaji kebutuhan orang tua anak autistik sebagai dasar perancangan dan pengembangan Model Pelatihan *Parent-Mediated Naturalistic Developmental Behavioural Intervention* (NDBI). Penelitian ini menggunakan pendekatan *Design and Development Research* (DDR), di mana pada Tahap I Analisis Kebutuhan dilakukan kajian literatur komprehensif serta wawancara kualitatif semi-terstruktur secara individual terhadap lima orang tua anak autistik. Hasil analisis tematik mengidentifikasi tiga tema utama, yaitu: (1) kurangnya pengetahuan dan keterbatasan akses terhadap intervensi perilaku; (2) peran orang tua sebagai agen intervensi utama di wilayah dengan sumber daya terbatas; dan (3) kebutuhan akan pendidikan serta pelatihan keterampilan orang tua dalam intervensi perilaku. Temuan ini menunjukkan adanya keinginan kuat dari orang tua untuk memperoleh pendidikan dan pelatihan yang terstruktur. Model Pelatihan NDBI Berbasis Orang Tua yang dikembangkan menyediakan kerangka acuan yang terstruktur dan dinamis bagi orang tua anak autistik untuk menerapkan strategi perkembangan dan perilaku berbasis bukti dalam rutinitas alami sehari-hari di rumah. Model pelatihan ini memiliki implikasi penting dalam penguatan pendidikan orang tua, peningkatan akses terhadap intervensi dini, serta menjadi acuan bagi pembuat kebijakan dalam mendorong layanan autisme yang lebih merata dan berkeadilan di berbagai konteks sosial, ekonomi, dan geografis di Malaysia.

Kata kunci: Analisis kebutuhan, intervensi berbasis orang tua, *naturalistic developmental behavioural intervention*, anak autistik, intervensi dini.

1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a multifactorial neurodevelopmental disability (Dahiya et al., 2022) that is characterised by impairment in social communication and interaction, restricted repetitive behaviours (RBB), interests, and activities (Parmeggiani, Corinaldesi & Posar, 2019; Kumar et al., 2019; Nuta, Koudys & O'Neill, 2021). It is estimated that around 1 in 100 children has been diagnosed with ASD worldwide (World Health Organization [WHO], 2022). Furthermore, recent reports by the Centers for Disease Control and Prevention (CDC), estimated that one in 36 children in the United States are diagnosed with ASD (Maenner et al., 2023). Therefore, the drastically increased prevalence of ASD worldwide (Baxter et al., 2015; Sharma, Gonda & Tarazi, 2018; Iles, 2021) draws concerns from multidisciplinary researchers to study early identification, diagnosis, and treatments of ASD and develop evidence-based interventions for autistic children as well as develop parents' training models or modules to improve both quality of life for parents and their autistic children.

Autistic children often exhibit a variety of challenging behaviours including aggression, tantrums, self-injury behaviour (SIB), property destruction, non-compliance with daily tasks, consuming inedible substances or pica, persistent screaming, hyper- or hypo-sensitivity to stimuli, elopement, obsessive behaviours, repetitive patterns of behaviours or motor stereotypes (Nuta et al., 2021; Abid et al., 2024; Tan et al., 2024). These difficulties of challenging behaviours create psychological distress for instance stress, anxiety, and depression that affect not only autistic children themselves but also their parents (Abid et al., 2024; Tan et al., 2024). The challenging behaviours negatively impact on autistic children's quality of life such as experiencing social rejection, restricting them from accessing community services, leading to interference in participation in social activities, and exposing themselves and their peers to injury risks (Argumedes et al., 2021; Tan et al., 2024). A systematic review by Chow et al (2024) revealed that families particularly parents of autistic children living in rural areas or belonging to lower socioeconomic groups, they face persistent obstacles including limited publicly funded services, expensive costs of private interventions, and geographical inaccessibility. Additionally, a study was conducted by Ab Hamid et al. (2023) showed empirical evidence on spatial accessibility in Selangor, Malaysia similarly demonstrates that rural areas experience significantly lower access to primary care services particularly for autism because affected by factors such as road density, distance to urban centres, and distribution of health facilities (Ab Hamid et al., 2023). These infrastructural challenges mirror the difficulties faced by parents of autistic children seeking specialised therapeutic services for their autistic children in rural areas, whereby interventions are often scarce, irregular, or entirely unavailable (Ab Hamid et al., 2023; Zhang et al., 2025).

In short, parents of autistic children particularly in low-resource areas such as rural areas encounter challenges when attempting to obtain medical, intervention, and educational services to support their autistic children's development and learning (Lee & Meadan, 2021). These include difficulty obtaining information related to ASD, long waiting lists in both government and private sectors' healthcare services, financial burdens and logistic barriers, local unavailability or limitation of providers with appropriate ASD-related services or trainings (Lee & Meadan, 2021; Glenn et al., 2022). Since there is a scarcity of trained professionals in low-resource areas, parent-mediated behavioural intervention emphasises on naturalistic intervention that shift the focus from interventions delivered by professionals in clinical settings to interventions delivered by natural change agents such as parents at home environment settings which is considered as the most natural and conducive environment for both parents and their autistic children (Lee & Meadan, 2021; Tan & Hosshan, 2024).

2. RESEARCH OBJECTIVES (RO) AND RESEARCH QUESTIONS (RQ)

Based on the problem statement, the approach of Design and Developmental Research (DDR) (Richey & Klein, 2007) as developmental research study is adopted to design and develop a Parent-Mediated Naturalistic Developmental Behavioural Intervention (NDBI) Training Model for parents of autistic children in low-resource areas.

Phase I: Needs Analysis of Parent-Mediated NDBI Training Model: -

RO1: To examine the needs of parents of autistic children to develop a Parent-Mediated NDBI training model for low-resource areas.

RQ1: What are the needs of parents of autistic children to develop a Parent-Mediated NDBI training model for low-resource areas?

3. METHODOLOGY

The needs analysis as a method to identify the gap between the current (what is) and targeted situation (what should be) (Fattah et al., 2021). Therefore, a thorough literature review study is conducted to identify the issues in problem statements, follow by an individual qualitative semi-structure interview that involves parents of autistic children from selected locations of Community-Based Rehabilitation (CBR). In this phase I needs analysis, an individual qualitative semi-structure in-depth interview with parents of autistic children in low-resource areas of low-income families to identify the needs to develop a Parent-Mediated NDBI Training Model in managing challenging behaviours of autistic children. A purposive and snowball sampling method is adopted to recruit five parents of autistic children to participate in an individual interview with researchers via the online platform Google Meeting. The interview was conducted for around 60 minutes. The interviews were audio and video recorded and then transcribed verbatim by the researcher. The transcribed verbatim documents were checked by supervisor and informants themselves (parents of autistic children) to ensure the quality and accuracy of the data.

Data were analysed inductively thematic analysis. Braun and Clarke's (2006) six phases of thematic analysis model are used for data analysis. The six phases of the thematic analysis model include: -

Phase 1: Familiarising the data by thorough reading the extracted information.

Phase 2: Generating initial codes from all potential items.

Phase 3: Searching for themes by analysing coded items, investigating relationships between the various codes, organising identified coded items and sorting them into preliminary themes and sub-themes.

Phase 4: Reviewing and refining themes.

Phase 5: Defining and naming themes and

Phase 6: Producing a report by providing a tabulated chart with finalised themes and indicating the narrative descriptions based on the themes (Braun & Clarke, 2006).

4. RESULT AND DISCUSSION

A thematic analysis was conducted to identify recurring patterns, concerns, and areas of need within the interview data. This is to explore the needs for support of parents of autistic children in developing a Parent-Mediated NDBI Training Model for low-resource areas. Therefore, the analysis was guided by Braun and Clarke's (2006) six-phase framework which provided a systematic approach for generating meaningful themes from narratives of participants. The six-phase framework comprises a sequential process beginning with familiarisation with the data, followed by generating initial codes, searching for potential themes, reviewing and refining these themes, defining and naming them, and finally producing the report.

In order to describe the needs for support of parents of autistic children in developing a Parent-Mediated NDBI Training Model for low-resource areas, there are three main themes: -

Theme 1 Lack of knowledge and limited access to behavioural intervention.

Theme 2 Parents as primary intervention agent in low-resource areas and

Theme 3 Need for parent education and skills training in behavioural intervention.

4.1. Theme 1: Lack of Knowledge and Limited Access to Behavioural Intervention

This theme highlighted the significant knowledge gaps and restricted access to behavioural intervention faced by parents of autistic children in low-resource areas. Parents explained that they were familiar with occupational therapy (OT), speech therapy (ST), and medical consultations, whereas behavioural approaches were largely unknown, inaccessible, or unavailable within their communities. The absence of exposure to evidence-based behavioural interventions left parents with limited strategies to manage their autistic children's challenging behaviours effectively. These findings emphasise the need for a Parent-Mediated NDBI Training Model that can equip parents with practical, accessible skills to address their autistic children's developmental and behavioural needs in contexts where professional

services are scarce. Within this theme, three sub-themes were identified and are presented in the following sections.

4.1.1. Sub-Theme 1.1: Lack of awareness of behavioural therapy

Parents revealed a limited awareness of behavioural therapy as an intervention option for autistic children. Parents were unknown or poorly understood about behavioural intervention because they were more familiar with occupational therapy and speech therapy. Some parents indicated that during consultations with doctors, they had never been informed or advised about behavioural therapy.

The following excerpt further illustrates this sub-theme:

Ya, occupational therapy. "Now he is just hyperactive... The occupational therapy is for him to have a better behaviour. (R1)

Doctor told me to continue with OT only. (R2)

None. I didn't know there was behavioural therapy, I didn't go looking for it. I don't know. (R3)

No, I don't know. I didn't look for behavioural therapy. I don't even know because the doctor didn't suggest anything about behavioural therapy (R4)

4.1.2. Sub-Theme 1.2: Lack of availability of behavioural therapy in rural areas

Parents living in rural areas reported that behavioural therapy services were largely unavailable within their communities. Parents mostly relied on occupational therapy in behavioural management of their autistic children. The unavailability of behavioural therapy in rural areas revealed the inequalities between urban and rural families in accessing appropriate care for their autistic children.

The following excerpt further illustrates this sub-theme:

Hmmmm.... I read about it but I don't know where to send him to behavioural therapy. I have no idea. None, I don't know. After all, we are outside the city, so there is limitation. Indeed, as far as I know, my friends who have children with autism really do not know here. (R2)

No. Didn't look for behavioural therapy. Nothing. No behavioural therapy services in my areas. (R4)

4.1.3. Sub-Theme 1.3: Reliance on pharmacotherapy

Some parents reported that doctors advised to adopt pharmacological treatments (medical management) to manage their autistic child's behaviours. Parents reported that doctors prescribed medications for their autistic children in managing the challenging behaviours. However, parents acknowledged that pharmacotherapy emerged side effects and the lack of complementary behavioural strategies to address fundamental developmental needs of the autistic children.

The following excerpt further illustrates this sub-theme:

Because the paediatrician once tried to give him medicine, Ritalin, because he was hyperactive. After a few months, the doctor said that seems to be a little cool down, we told doctor that it is worse that we want to control him, because he is still.... That's it if he cries, he cries badly if he wants to rage, he's even worse. Since the day the doctor said it's okay, stop it. No need to give it, he said if you don't give medicine, you can control it. We say that instead of taking medicine, it is better not to take medicine. More people say he looks calmer; he's not that bad anymore. The more he has taken medicine, the more people say he rages, the louder he cries, the worse he is. That was the last time the doctor decided not to take medicine. (R2)

4.2. Theme 2: Parents as Primary Intervention Agent in Low-Resource Areas

Parents highlighted that they were considered as the central role in implementing interventions for their autistic children at home setting. Their responsibilities extended beyond routine caregiving to include teaching skills, managing challenging behaviours, and creating structured home environments that supported their autistic children's learning and development. Parents described themselves as both caregivers and educators, adapting strategies to their autistic child's unique needs despite having limited formal training. Therefore, parents should be equipped with evidence-based and practical strategies to enable them to act effectively as primary agents of intervention to support their autistic children's progress and development in low-resource areas. Within this theme, three sub-themes were identified and are presented in the following sections.

4.2.1. Sub-Theme 2.1: Parents play a vital role in home-based intervention

Parents in low-resource areas recognised their pivotal role in delivering home-based interventions for their autistic children. Parents could integrate intervention strategies into daily routines such as mealtime, bathtime, or household tasks together with family interaction provided natural opportunities for their autistic children to explore, learn, and acquire the necessary learning skills. Therefore, parents were able to create consistent and meaningful learning experiences for their autistic children at home. Parents reported that their active parental involvement was a necessity in low-resource areas for promoting positive behavioural and developmental outcomes.

The following excerpt further illustrates this sub-theme:

The role of parents is apparently important. Can't rely on others. (R1)

If we take him to go to almost 10 therapies, even if we don't work hard to recover him. It doesn't work. It won't be good. (R1)

Because OT is only for a moment. If it's OT, it's not even an hour, it's usually half an hour. After that, parents usually continue in the house. Because if you expect hospital therapy, it is really very very very little effect. (R3)

Oh, it must be very important, yes. The role of parents is very important. Yes, of course. Because who else wants to show, want to take care of the child, want to show a good example to the child, the parents are the ones for sure, right. (R4)

4.2.2. Sub-Theme 2.2: Parents need positive attitudes, self-initiative, and determination

Parents highlighted that sustaining their role as primary intervention agents required them to cultivate positive attitudes, self-initiative, and determination. These motivated parents to maintain optimism and resilience when encountered the uncertainties of their autistic child's developmental journey; to seek information, adapt strategies, and implement interventions at home; to remain committed despite emotional strain, financial hardship, and societal stigma. This positive mentality traits enabled parents to sustain long-term caregiving and intervention efforts for their autistic children in lowresource areas.

The following excerpt further illustrates this sub-theme:

The first thing is that parents have an important role. We have to sacrifice a little of our time and energy for a child like this. He will recover; we just have to be patient. (R1)

Parents must continue intervention activities at home. Autistic child most of the time with us. So, parents have to work harder and be patient. (R5)

4.2.3. Sub-Theme 2.3: Parents know their child's needs better

Parents emphasised their unique insight into their autistic children's behaviours, preferences, and developmental needs. Parents developed a deep understanding of their child's triggers, strengths, and areas requiring support through their daily caregiving experiences. Hence, parents considered as essential partners in designing and implementing effective interventions. Parents played a role not only as caregivers but also as knowledgeable co-interventionists for their autistic children in low-resource areas.

The following excerpt further illustrates this sub-theme:

Because our children are special. So, we are the only ones who can understand better the cares of autistic child. It's usually the husband and wife who understand better the children (R2)

4.3. Theme 3: Need for Parent Education and Skills Training in Behavioural Intervention

This theme highlighted parents' strong desire for structured education and training that would equip them with practical skills in behavioural intervention. Parents explained that they were familiar with therapies such as occupational and speech therapy, however they lacked of evidence-based strategies on how to manage challenging behaviours of their autistic children in everyday home settings. Therefore, parents considered training programmes as essential for building their competence, confidence, and capacity to act as intervention agents for their autistic children in low-resource areas. Within this theme, two sub-themes were identified and are presented in the following sections.

4.3.1 Sub-Theme 3.1: High demand for parent-mediated NDBI training

Parents expressed a strong demand for parent-mediated NDBI training. They highlighted that a parent-focused training model would empower them with both knowledge and practical skills to implement evidence-based strategies within daily routines for managing challenging behaviours of their autistic children at home.

The following excerpt further illustrates this sub-theme:

I support it if you do some kind of training for this parentwant to teach our child, want to get him out of the problems he's facing. (R1)

Yes, I think it's really necessary to have parent training. (R2)

I think it's necessary, it's necessary. It is necessary that there is a lack of facilities even outside the city. It is necessary for educational parents training to gain knowledge and techniques. (R4)

Yes, of course needed for parent education training. (R5)

4.3.2 Sub-Theme 3.2: Training needs to focus on behaviour management skills

Parents highlighted that training programmes should prioritise behaviour management skills in order to learn how to respond effectively to challenging behaviours of their autistic children in low-resource areas. It would reduce parents' daily stress, improve family functioning, and enhance their autistic children's developmental progress. Parents emphasised that the importance of practical, hands-on strategies that could be applied consistently at home and adapted to their autistic child's unique needs.

The following excerpt further illustrates this sub-theme:

It is very necessary. I think it is very necessary actually for parents to have parent training intervention. I think it is very necessary to educate the parents of the behavioural training. Yup, that's right. More knowledge and insight. (R3)

Very good. I hope many more mothers and fathers out there who have children with autism will join and share their problems. Most parents are embarrassed to have children like this. So don't be shy.

Just sharing any problems with the public. More trainings about managing behaviours of children with autism. (R4)

Table 1 presents the themes and sub-themes highlight the needs for support of parents of autistic children in developing a Parent-Mediated NDBI Training Model for low-resource areas, which offering a structured overview of the issues identified through thematic analysis.

Table 1. Themes and Sub-Themes: The Needs for Support of Parents of Autistic Children in Developing a Parent-Mediated NDBI Training Model for Low-Resource Areas

| No. | Themes | Sub-Themes |
|-----|---|--|
| 1. | Lack of knowledge and limited access to behavioural intervention | 1.1 Lack of awareness of behavioural therapy 1.2 Lack of availability of behavioural therapy in rural areas 1.3 Reliance on pharmacotherapy |
| 2. | Parents as primary intervention agent in low-resource areas | 2.1 Parents play a vital role in home-based intervention 2.2 Parents need positive attitudes, self-initiative, and determination 2.3 Parents know their child's needs better |
| 3. | Need for parent education and skills training in behavioural intervention | 3.1 High demand for parent-mediated NDBI training 3.2 Training needs to focus on behaviour management skills |

The first major theme emerging from this study highlights a critical and multifaceted challenge faced by parents in low-resource areas which are the lack of knowledge about evidence-based behavioural interventions and the limited availability of these services in rural or underdeveloped areas (Lee & Meadan, 2021). These constraints not only hinder early intervention efforts but also exacerbate feelings of helplessness among caregivers, who often resort to less effective or inappropriate strategies (Naithani et al., 2022). The findings underscore the urgent need for a contextually adapted, parent-mediated Naturalistic Developmental Behavioural Intervention (NDBI) training model that addresses knowledge deficits, bridges accessibility gaps, and empowers parents as agents of change within their local environments (Tan et al., 2024; Tan & Hosshan, 2024). The theme underscores the central role of parents as the most consistent, accessible, and sustainable intervention agents for their autistic children, particularly in low-resource areas where access to professional services is scarce or delayed. The findings affirm that empowering parents to deliver NDBIs within the home setting is not only a necessity but also a pragmatic and culturally relevant solution in these contexts. It reflects parents lived realities, highlighting their capacity, commitment, and insightful understanding of their autistic children, thus qualities that position them as ideal facilitators of early developmental and behavioural interventions when appropriately supported. The theme captures the critical and urgent need expressed by parents for formal education and hands-on training in behavioural intervention techniques, specifically within the context of a Parent-Mediated NDBI Training Model. In low-resource areas, where access to professional support is often inconsistent or absent, parents are expected to serve as the primary implementers of intervention (Masri et al., 2023). However, without adequate knowledge and skill, even the most motivated caregivers struggle to apply effective behavioural strategies consistently. The theme highlights parents' recognition of their central role, their willingness to be trained, and their desire for capacity building, particularly in managing their autistic children's challenging behaviours in everyday contexts.

5. RECOMMENDATION FOR THE FUTURE RESEARCH

The future researchers should explore the scalability and adaptability of the Parent-Mediated (NDBI) Training Model across diverse cultural and linguistic contexts within Malaysia and other low- and middle-income countries (LMICs). The diversity of Malaysia's population including Malay, Chinese, Indian, and Orang Asli communities presents a rich opportunity to examine how sociocultural beliefs, parenting practices, and communication norms influence parental engagement in behavioural interventions. Comparative studies across ethnic groups and regions could identify culturally specific adaptations that maintain fidelity to NDBI principles while enhancing acceptability and feasibility. Moreover, translation and cross-linguistic validation of training materials in Bahasa Malaysia, Mandarin, and Tamil will improve inclusivity and accessibility for parents from various educational backgrounds. In addition, future research should investigate the inter-professional collaboration and community ecosystem required to sustain parent-mediated models. Partnerships between parents, teachers, health professionals, and community organisations can form an integrated support network that enhances continuity of care. Mixed-method evaluations can assess how collaboration at microsystem (family), mesosystem (school/community), and macrosystem (policy) levels influences the effectiveness and sustainability of Parent-Mediated (NDBI) Training Model. Additionally, exploring the role of non-specialists such as trained paraprofessionals, early childhood educators, and community health workers in extending the reach of interventions could provide insights into cost-effective and scalable implementation.

6. CONCLUSION

In conclusion, this study advances the discourse on early autism intervention by proposing a rigorously developed, Parent-Mediated (NDBI) Training Model specifically tailored for low-resource areas. It bridges the gap between global evidence-based practices and local realities in Malaysia by centring the voices, strengths, and challenges of parents. The findings reinforce the argument that parental empowerment through structured training is not only a cost-effective intervention strategy but also a transformative one capable of improving child outcomes, reducing parental stress, and strengthening community inclusion.

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