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Intervention for Children with Neurodevelopmental Disorders: Narrative Review

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ABSTRACT

Neurodevelopmental disorder (NDD) is a world-wide public health issue that particularly affects children in low- and middle-income countries. Early diagnosis, intervention, and rehabilitation are primary ways to aid children's functioning skills according to their diverse needs with neurodevelopmental disorders (NDD) and also those of their parents. The WHO's International Classification of Functioning, Disability, and Health (ICF) Framework focuses on a child's health beyond biomedical deficits, using the concept of functioning to measure development concerning this construct. In case of ICF-CY which was developed for children and youth but measurement tool is difficult to understand to be used for children, also CFM developed by UNICEF, is a gross tool for children. This narrative review aims to identify early participatory intervention measures for children with NDD that are based on the ICF, as described in the literature. Incorporating with this ICF framework many researchers have introduced intervention to the children with NDD but still there is a huge gap for screening and early intervention at baseline level. This review used a systematic search procedure with various health-related databases (Frontiers, research gate, PubMed, google scholar), and identified family focused intervention that provide support to children with NDD in paediatric health in different settings. In India, approximately 2.3 million children below six years of age group have some developmental disability, and many of them are from rural and semi-urban areas with minimum access to early intervention services. Results showed that the children with NDD who participated in those interventions showed improvement in all domains with both the intensive and regular services. It was also observed that including parents' participation in therapy sessions enhanced the programme outcomes. Participation and activities are the most common ICF domains, as per the framework.

Keywords: *Children, NDD, Participatory Intervention, ICF*

1. INTRODUCTION

The basic structure construction of brain is an ongoing process which starts before birth and then it continues. The quality of this construction may be affected by early experiences, which can lead to either a strong or a fragile foundation for health, behaviour, and learning. The first few years of life are very important for building neural connections in the brain. After this period, "pruning" occurs to activate brain circuits. First, sensory pathways for basic vision and hearing develop, then early language skills and higher cognitive functions develop.[1]

Child participation in different games and activities improves his or her health and well-being, which promotes his or her development, self-efficacy, and also their motor, cognitive, emotional, and social skills.[2]

DSM V (5th Edition) defines Neurodevelopmental disorders (NDD), as a group of disorders that characterised by some problems which may arise during a child's early developmental period and are characterised by developmental deficits that may affect the child's personal, cognitive, academic, social, and also emotional wellbeing. There are different types of NDD, like autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), developmental coordination disorder, learning disorders, language disorders and motor disorders.[3]

Children with neurodevelopmental problems may experience some difficulties like language and speech difficulties, motor skills difficulties, behavioural difficulties, memory problem, learning difficulties, or other neurological functions delay and developmental milestones delay are anticipated.[4] **Neurodevelopmental disorders are disabilities** primarily they are associated with the functioning of the nervous system and brain.

The World Health Organization (WHO) states that disability is "as an umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual (environmental and personal) factors". The ICF (International classification of functioning) framework defines functioning as an umbrella that denotes the interactions of four domains, i.e., body function and structures, activities, participation, and contextual factors, examining the positive or neutral aspects occurring between the individual's health condition(s) and their context. On other hand disability is an alternate part of umbrella where interaction of these four domains interaction alters.[5]

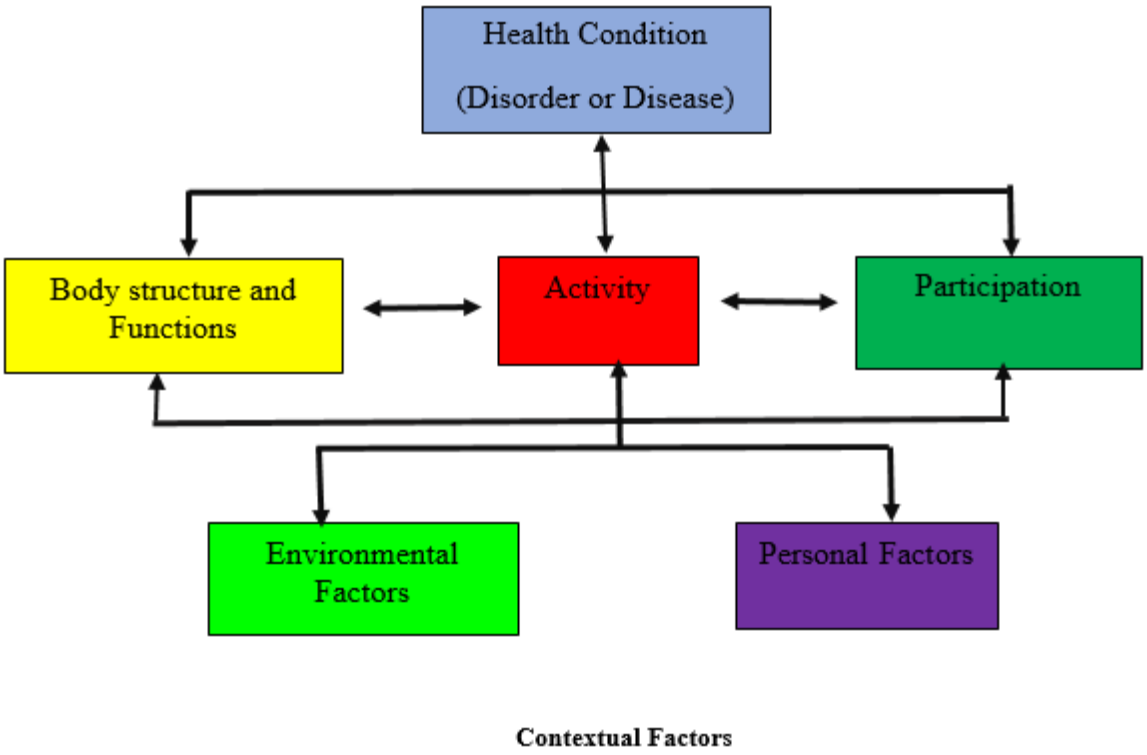

Figure 1: International classification of functioning, disability, and health framework

Neurodevelopmental disorders

As per DSM-5, neurodevelopmental disorders are a group of conditions that start at an early stage of development and are characterised by "developmental deficits that can produce impairments of personal, social, academic, or occupational functioning"[3] These neurodevelopmental disorders include motor disorders (developmental coordination disorder, or DCD), intellectual disability (ID), communication disorders, cerebral palsy (CP), autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), tic disorders, and specific learning disorders. Very often, it can be seen that two or more types of disorders occur simultaneously, like how ID often occurs together with cerebral palsy (APA, 2013; Patel, Greydanus, Omar, & Merrick, 2011). Most common types, like the autism spectrum and cerebral palsy (CP), occur together in a child. Spina bifida and muscular dystrophy, which are congenital problems that can also be associated with the central nervous system and neuromuscular and musculoskeletal conditions (Disability World, 2019), are not mentioned within the NDD. All children have the same needs and rights to participate in activities and not be left behind for their engagement in those activities (UN, 2013). [7]

Prevalence of NDD

In 2015, Sustainable Development in the adoption of the 2030 Agenda was framed with the pledge that no one will be left behind. It aims that169 targets of all 17 Sustainable Development Goals (SDGs), will be achieved for the wellbeing of society members. It also emphasises to cover those who belongs to hindmost, which also includes those children with functional disabilities and also their surroundings. [7]

In the scientific literature, according to the DSM-5 (2013) criteria, the prevalence of NDDs is highest in people under the age of 18. As per the report the prevalence rates are: motor disorders (MDs) are 0.76–17%, Attention-deficit hyperactivity disorder (ADHD) is 5–11%, Specific learning disorder (SLD) are 3–10%, Communication disorders (CDs) are 1–3.42%, Intellectual disability (ID) are 0.63%, autism spectrum disorder (ASD) is 0.70–3% and intellectual disability (ID) are 0.63%.[6]

Tools developed for Identification of NDD

In 2011, based on the ICF framework the Model Disability Survey (MDS) tool which was developed by WHO and the World Bank Group to collect data on functioning and disability. [8] Primarily, it was designed as independent survey for household adult with a cutter version which will cover health and other population surveys. They were for continuous monitoring of functioning and disability. There was also an optional module for children, which will elicit information regarding health conditions, diagnosis, and treatment from the respondents.

In 2020, WHO collaborated with IHME and tried to estimate the prevalence of those persons who experienced a health condition or disability over the period. And also tried to estimate whether rehabilitation is useful for these persons or not based on the Global Burden of Disease (GBD) 2019 database.[9] This tool was named the **WHO Rehabilitation Need Estimator.** A group of experts in the field of rehabilitation was gathered by the WHO to collect data on specific health conditions among all age groups those who need rehabilitation as a key intervention comes under treatment plan. Sample size of 25 health conditions were selected for this study. And for the first time, cerebral palsy was recognised as an important independent unit in the GBD database, whereas epilepsy and ADHD were included under category of developmental disabilities in children.[10] Therefore, six developmental disabilities were reported in the substantive GBD 2019 database (https://vizhub.healthdata.org/gbd-results/). Therefore, it was decided by experts to include all children who have developmental disabilities and who need rehabilitation. The disabilities that were included are **hearing loss, vision loss, developmental intellectual disability, epilepsy, autism spectrum disorders, and ADHD.** The GBD database already detected a huge number of cerebral palsy cases among the estimated children with developmental intellectual disability.[11] It was also reported that these children younger than 5 years with cerebral palsy and intellectual disability needs rehabilitation.[14]

In 2016, UNICEF developed a module for child functioning named CFM (Child Functioning Module) in partnership with the Washington Group for inclusion in its routine Multiple Indicator Cluster Survey (MICS) implemented worldwide. The CFM mainly follows the bio-psychosocial model of disability and focuses on the presence and extent of difficulties in children's functional skills. This module is available in two versions, one for 2–4-year-olds and the other for 5–17-year-olds. Eight developmental domains are covered by this module: hearing, vision, mobility, fine motor, communication/comprehension, emotions, learning, and playing; and both are designed for administration to mothers and primary care givers. A 4-level Likert rating scale was used to get responses, which can enlighten the levels of severity (0 means no difficulty, 1 means there is some difficulty, 2 means a lot of difficulty, and 3 means they cannot do at all). This scale allows for the detection of children with mild difficulties (those who respond "at least some difficulty"), moderate difficulties (those who respond "a lot of difficulty"), or severe difficulties (those who respond "cannot do at all").

In 2021, UNICEF published their first report, and used 103 data sources multinationally to collect the data, which represents eighty four percent of the world's child population and at least fifty percent of children in each region of the world.[12] By using two different instruments (the UNICEF/Washington Group Child Functioning Module and the Washington Group Short Set on Functioning; later, the final reports were harmonized), UNICEF collected the data. After data harmonization, children aged 2 to 4 years have mainly problems in vision (even one using glasses), hearing (though one using a hearing aid), walking (even one required for any assistance walking or equipment), cognition or being understood when speaking, fine motor activities like picking up small objects using their hands, or learning new things, or playing with freinds. In the case of children aged 5 to 17 who reportedly seem very anxious, nervous, or worried and/or very sad or depressed on a daily basis and/or they have problems in vision (even one using any glasses or contact lenses), hearing (though one using any hearing aid), walking on ground level (even one using equipment or assistance), gross motor like performing daily activities, such as feeding or dressing themselves, and cognition like being understood when speaking to people socially. Learning new things and remembering those things, concentrating on the activity they like, accepting some changes in their routine (if needed), any behaviour controlling activities, and making new friends, seems that the result provides an indication of the prevalence of moderate-to-severe functional difficulties, not any epidemiological characteristics of any disease or impairment.[12]

Intervention for NDD

As per ICF children and youth version, Family Participation Related Construct (f PRC) framework is one of most important constructual framework, which states participation of a person means involvement in a life situation, and which is one domain of the six core domains of that framework (WHO, 2015, p. 9).[5] Imms and her colleagues focused on the term "participation," which emphasises the family of participation-related constructs (f PRC). In this framework, participation can be treated both as an entry point and as an outcome of health and educational services. There are two main components, i.e., attendance and involvement, which describe participation in that framework. Involvement of a person means he / she participate in an occupation then engaged and also connected socially to others. To ensure a person's attendance, two things to be measured positively one is, his/ her attendance frequency and other one is the extent of diversity of the participatory activity. It is also

important to mention the person's intrinsic factors concerning participation. "Activity competence includes cognitive, physical, and affective skills and abilities measured by capacity, capability, and performance". Along with activity competence, importance should be given to the children's sense of self, which includes self-efficacy, autonomy, and satisfaction. Opportunity should be given to children for increasing children's preferences to experience meaningful and valuable activities (Imms et al., 2015; Imms et al., 2016). Beside the intrinsic ones, the ICF-CY framework also talks about the extrinsic ones, which is also related to participation. These extrinsic factors mentioned about the relationship between the environment and individual's participation. The environment (that means physical and social), both directly and indirectly, can affect the individual's participation, which occurs within a contextualised setting. The contextualised setting includes people, objects, settings, and any participatory activity. The interaction of place, activity, people, objects, and time shapes a person's contextualised experience during his or her participation. As a consequence, changes occur in people and the environment as the relationship between the person and his or her surrounding context alternates over time (Imms et al., 2016).[2]

In Sub-Saharan Africa many a time it is seen that, late diagnosis and interventions of neurodevelopmental disorders (NDD) in children, despite of usual early parental concern about development. As a result of this, for children with Neurodevelopmental disorder in this region, has not achieved optimal functioning. Any form of education was inaccessible to many of children and as a result there was impairment in expressive language ability. In 2014, MHIN Africa innovated a programme which have measured the impact of early screening in improving, identification and instituting early interventions to improve prognosis for the children with neurodevelopmental disorders. The programme approach consists of three measures, which are as follows:

- Combining the screening process and information for parents regarding core package into routine primary health care
- Improving children's access to evidence-based care which will be provided by training health personnel.
- Including assessment for functional impairment and disability.

This project tried to introduce and incorporate routine surveillance and screening for children with neurodevelopmental disorders into the National Programme on Immunization (NPI), which is an already well-established programme at primary health care levels in Nigeria and other Sub-Saharan African countries. This project consisted of:

- Combine screening process and core packages of services into routine PHC, which means they wanted to do surveillance and screening of those children with neurodevelopmental disorders who would be included in the national programme on immunisation at the PHC level and also provide intervention to the parents regarding NDD.
- Improve Children's Access to Evidence-Based Care by Trained Health Personnels which means this project trained PHC health personnel and also multidisciplinary professionals at tertiary level of health care to improve their knowledge and skills to develop skills to identify NDD in children under age of three in early stage, also provided Individualised family service plan.
- Incorporate Functional Impairment and Disability into Assessment which means disability assessment tools was used during surveillance or screening and evaluation/Individual tailored interventions, to assess functional impairment and disability both at early stage and at various stages of interventions.

The primary target population for this project was the subset of children in two selected local government areas who were undergoing immunisation schedules under NPI at the PHC level in Lagos, Nigeria. 3,011 children at particular stages of screening like 3 to 6 months, 6 to 12 months, 18 to 24 months, and 24 to 36 months these four stages based on children's age-related visits were screened during immunisation, for Neuro developmental disorder at primary care level, and 0.9% of these screened positive for one or more diagnoses of neurodevelopmental disorder.

Developmental trajectory and developmental milestones, cognitive trajectory and education needs assessment, adaptive functioning, biomedical profile, physical health problems, and nutritional components were evaluated by clinicians.

Interventions include Individualized Family Service Plan (IFSP) was developed through the results of the Definitive Evaluation of the child. This project also talked about how the interventions for each child and family will be individualised based on available facilities. Facilities will provide interventions, which may include educating affected parents about NDD and also counselling and supporting the family by establishing family support groups at the PHC level, where parents can share their anxiety and concerns before referral to a tertiary level of health care centre for further evaluation and specific interventions. [16]

An organization in West Bengal has implemented a home-based early intervention (HBEI) program for underprivileged children with neurodevelopmental disorders in a rural block of Purulia district. The geographical terrain of the region is difficult to navigate, and access to healthcare is further constrained by the considerable distance to the nearest district hospital. To operationalize the program, a multidisciplinary team consisting of developmental paediatricians and therapists recruited

local residents with at least a graduate-level education. These recruits were subsequently provided with a structured seven-day training program in child development to enable delivery of community-based intervention services. This programme included knowledge and practical skills related to improving developmental milestones, the recognition of red flags, how to administer the modified Trivandrum Development Screening Chart, and common, successful home-based care that were using as early intervention. Following this, they were also given the tag of "community therapy providers". A team comprising experts and trained Community therapy providers conducted a developmental screening camp to assess children with developmental delay and any neurodevelopmental problems, which can be treated by early home-based intervention, in children under 6 years of age in selected blocks in Purulia. This screening identified 122 children who were screen positive, out of whom 76 families consented to become a part of the home based early intervention program. A detailed assessment done by the developmental paediatrician that involved clinical evaluation and the use of the following tools: The Gross Motor Function Classification Scale.[17]

2. DISCUSSION

Very often, there is a substantial delay in the diagnosis of the patients referred for a NDD assessment; e.g., findings of a recent randomised controlled trial showed that 40% of families were referred for assessment of ADHD and still awaiting for a diagnosis which was six months after the initial assessment.[18] After diagnosed those families report significant delays in commencement of treatment but still there was inadequate treatment monitoring.[19] As a result of these type of delays and also a limited access particularly in geographically remote regions to treatment, children may not be fully benefited from the intervention, which may have a later effect on their social, societal and academic performance in future. there are also some reasons for delay in service delivery for NDD which include lack of access remote geographical area to trained therapists[20] just like as the study in Purulia, West Bengal [17], and insufficient clinical time to deliver best care practices[21]. As per the study of Purulia, 122 children were identified as positive after the screening process, but only 76 families consented to being enrolled in the HBEI program. [17] So here we can see that there is a tendency of families for less participation and also that cause a delay in starting diagnosis of NDD. As per the ICF framework, both the Participation and Activities domains were predominantly represented throughout all measures. We can also see that in Africa MPHIN has tried to integrate the screening and core packages of information for parents into routine primary health care and also tried to improve children's access to evidence-based care by trained health providers. So, they targeted population whoever undergoing Immunization Schedules under NPI at PHC level in two selected Local Government Areas (LGA) in Lagos State, Nigeria, as National Immunization Schedule participation of children would be at cent percent.

3. CONCLUSION

This narrative review serves as a resource for researchers by highlighting the use of participatory activity measures within the International Classification of Functioning, Disability and Health (ICF) framework for children with neurodevelopmental disorders (NDD). Examining how early intervention can be aligned with these measures provides insights into patterns of participation and allows for the identification of gaps in care delivery. There is a pressing need to systematically address these gaps and to strengthen participation outcomes for individuals with NDD across age groups and diverse settings, guided by the ICF framework.

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