



**ORIGINAL RESEARCH PAPER**

**Neurological Sciences**

**THE DEVELOPMENT AND VALIDATION OF AN ICF CHECKLIST FOR NEURODEVELOPMENTAL DISABILITY**

**KEY WORDS:** NDD, ICF, CBCL, GDS and VSMS.

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**ABSTRACT**

**Background:** The International Classification of Functioning (ICF) provides a universal framework for defining and classifying functioning and disability worldwide. To facilitate the application of the ICF in practice, ICF based-tools like the "ICF Core Sets" are being developed such as ICF-CY Core Sets for Children and Youth. **Objectives:** The current study aimed (a) To develop an ICF based checklist for Neurodevelopmental Disability (NDD); (b) To validate the developed checklist. **Materials and Methods:** Constructs of the outcome measures identified in studies were linked to the ICF-NDD by the trained professionals by the Delphi Consensus Process. A total of 420 children were recruited into the study, where 300 having been diagnosed with NDD and 120 normal children. All the children were subjected to gold standard battery of scales like Child Behavior Check List (CBCL), Gessel Developmental Schedules (GDS) and Vineland Social Maturity Scale (VSMS) along with developed ICF NDD checklist. While developing the checklist, outcome measures from assessment battery were linked to the ICF-NDD and covered 90 independent ICF-NDD categories. Out of the 90 categories, 26 (28.9 %) were related to body functions, 31 (34.4 %) were related to activities/participation, 21 (23.3 %) were related to environmental factors, and 12 (13.3 %) were related to body structures. This provides information about content of measures that may guide researchers and clinicians in their selection of an outcome measure for use in a study and/or clinical practice in children with NDD. **Results:** The developed ICF NDD checklist has demonstrated good psychometric properties, with consistently high reliability (Cronbach's  $\alpha$  0.839) and concurrent validity with CBCL ( $r = 0.854, p = 0.05$ ). Analyses of Variance (ANOVA), Pearson's Coefficient proved our hypothesis that children with Autism NDD are 3 times more disabled than other NDD patient groups like Cerebral Palsy, Down's Syndrome, Learning Disability and Mental Retardation. **Conclusion:** Based on the above findings, we may claim that ICF NDD checklist is at par with other scales like CBCL, GDS, and VSMS for the assessment of disability in NDD with an advantage in identifying more subjects with hitherto unidentified health and disability issues, early diagnosis, disability grading / status, therapy and adequate follow up. As the larger population of participants for this study was drawn from institutions for special needs, the ICF-NDD checklist will have to be applied to a larger community living population of children with Neuro-Developmental Disability before being subjected to wider application.

**INTRODUCTION**

**Background Of The Study**

Approximately 400,000 preschool children have a major neurodevelopmental disorder impacting on mobility, cognitive-adaptive, or communicative skills. As many as 1 in 3 children live at psychosocial disadvantage because of poverty, parental mental illness or substance misuse, or low parental educational (i.e. less than high school). In the past decade over 500,000 preschool children have survived being born with very low birth weight or extremely low birth weight status<sup>1</sup>.

**Neuro-Developmental Disability (NDD)**

Neurodevelopmental disability is a global construct that describes the spectrum of dysfunction that affects children with impaired cerebral development and cerebral dysfunction. It encompasses within it motor, cognitive, behavioral and social disability all of which affect children in varying levels of functioning<sup>2</sup>.

However, most families see their child's most apparent problem as the visible disability and will focus more medical attention on this disability at the risk of overlooking routine well child care<sup>3</sup>.

A continuing need for research about and support of young people with cerebral palsy is necessary to try to improve their life circumstances. Equally important, in keeping with the model of the International Classification of Function, is the need for continuous advocacy within our society to promote full integration of adults with disabilities<sup>4</sup>.

Down syndrome (DS) is the most common genetic cause of mental retardation (MR) with a reported prevalence of epilepsy of 1-13%<sup>5</sup>.

Down syndrome is caused by the presence of the whole or part of an extra copy of chromosome 21<sup>6</sup>. Estimation of the incidence of Down syndrome in India is 1 in 800 live births<sup>7</sup>.

Co-morbidity with mental retardation, epilepsy, disruptive behaviors and learning difficulty is not uncommon. Although there is currently no known cure for autism there is evidence to suggest that early intervention therapy can improve functioning of autistic children. Judicious use of psychotropic drugs is necessary to manage associated aggression, hyperactivity, self-mutilation, temper tantrums; but drugs are not a substitute for behavioral and educational interventions. The family physician can play an important role in detecting autism early, coordinating its assessment and treatment, counseling the parents and classroom teacher, and monitoring the child's progress on a long term basis<sup>8</sup>.

Learning Disorders are common among elementary school children<sup>9</sup>. Existing reports indicate that 10% to 16% of the school children have special needs<sup>10</sup>. Usually 3-5 children in each classroom will present with some impediment to learning apart from intellectual social deficits or emotional disturbances<sup>10</sup>. Studies have shown that less than 40% of children with learning disabilities complete grade 12 and unemployment rates, social adjustment, marital problems and delinquency are higher in adult individuals with learning

disabilities<sup>11</sup>.

Learning disabled children are thought to have significant deficits in learning relative to expectations based on the individual's age and intellectual ability which cannot be completely explained by environment or other psychological symptoms<sup>12</sup>.

To explain the learning problems in these children, the "Neuropsychological theories" of learning disabilities have used a cybernetic model, based on steps that occur during a learning process. These steps are "Input-Integration-Memory and Output". Learning disability can occur due to impaired ability to carry out any of these steps<sup>13,14</sup>.

Most teachers and psychologists are familiar with the movement problems, both gross and fine, that often accompany a learning disability<sup>15</sup>. Ismail and Gruber (1967) confirm the expectation that children lacking in early motor experiences encounter difficulty in learning as measured by achievement and intelligence tests<sup>16</sup>.

Motor development is thought to create an opportunity for cognitive function to develop which in turn broadens a child's opportunity for motor development<sup>17</sup>. But the precise role of motor development in cognitive functioning has not been determined<sup>18</sup>.

Further investigations of Learning disabled and non learning disabled students on a wide range of motor skill tasks is needed both for the purpose of increasing understanding of motor characteristics of learning disabled students and for the purpose of designing more effective motor training programs<sup>19</sup>.

The term "Learning Disabled" is most often used to describe heterogeneous population of children who display persistent school achievement problems that are not easily explained by poor intellectual abilities<sup>20</sup>.

In most cases, onset of Learning disability is noticed between preschool and second grade. Boys usually outnumber girls by 2:1 to 4:1 ratio<sup>21</sup>.

Among the three types of learning disabilities, two subtypes considered in this study are: Reading disorder is characterized by deficits in reading achievement relative to age and intelligence<sup>21</sup>.

At least one in five children has been found to have significant difficulty in reading<sup>22</sup>. Evidence clearly demonstrates that most school age children fail to catch up with their peers despite of having good reasoning skills and adequate abilities in other domains of learning<sup>23</sup>. Acquisition of reading related skills requires the coordination of many areas in brain involved in visual, motor and cognitive activities. Thus, dyslexia can result from defects in any of the above processes<sup>24</sup>.

Children with dysgraphia have specific difficulties in written language production<sup>25</sup>. Difficulties with written expression are often unidentified and can be masked by reading disorders or considered to be due to poor motivation<sup>26</sup>.

It has been seen that motor dysfunctions exert a unique effect upon writing. In some cases they result in relatively illegible handwriting in these children<sup>26</sup>.

Some people with learning disability may have trouble coordinating the groups of large muscles (gross motor disability); others have difficulty in coordinating small groups of muscles (fine motor disability)<sup>27</sup>. Results from number of studies indicate that learning disabled subjects generally score lower than non-handicapped subjects on various motor

tasks<sup>28</sup>.

Fine motor problems become recognizable during skills such as writing, drawing, using scissors, tying shoelaces etc<sup>28</sup>.

Due to lack of coordination, they are unable to move the muscles in a smooth manner. At young age, the sign of poor coordination may be slow achievement of developmental milestones. Child may have difficulty in activities like throwing a ball, skipping or running and may trip frequently<sup>30</sup>. Children with dyslexia sometimes have balance and motor-coordination disorders in attention demanding circumstances<sup>31</sup>.

### International Classification Of Functioning – Child And Youth Version (ICF-CY)

International Classification of Functioning, Disability and Health (ICF) is World Health Organization (WHO) frame work for health and disability<sup>32</sup>. It is a universal classification of disability and health for use in health and health-related sectors. With the approval of new ICF, we can rely on a globally agreed framework and classification to define problems in functioning of patients with NDD. The advantage of ICF is the application of it in clinical areas and thus condition specific health status measure could be developed<sup>33</sup>.

Implementation of the ICF itself, showed great promise in improving the quality of health care services for individuals across the world, generating innovative outcome-based research and proactively influencing culturally sensitive global health policy<sup>34</sup>. It was stated that the ICF conceptualizes functioning from holistic and lived experience vantage points, thereby allowing for planning interventions targeted at the whole individual or the environment<sup>35</sup>.

During the last decade, under the World Health Organization's direction, the International Classification of Functioning, Disability and Health (ICF) has become a reference tool for monitoring and developing various policies addressing people with disability. The study presented three steps to increase the semantic interoperability of ICF: first, the representation of ICF using ontology tools; second, the alignment to upper-level ontologies; and third, the use of these tools to implement semantic mappings between ICF and other tools, such as disability assessment instruments, health classifications, and at least partially formalized terminologies<sup>36</sup>.

### NEED FOR THE STUDY

With the ICF categories and ICF-CY core Set categories, tweaked to relevant and reasonable size of NDD evaluation, as well thought out thesis goal, could serve as a global assessment checklist for NDD with culture specific modifications. This was a primary need which was considered.

There are several published ICF-CY composite scores available. However, no systematic framework that covers the spectrum of NDD symptoms and problems related to functioning and especially with relevance to our Indian community lifestyle has been established thus far. With the alarming increase in the prevalence of NDD not only in urban India, but also in rural India, there seems to be an urgent need to develop and validate an ICF checklist of NDD relevant to our community life, holistic in approach, but at the same time sensitive, to aid early diagnosis and interventions.

### AIMS

To develop and validate the International Classification of Functioning, Disability and Health (ICF) based checklist for children with Neuro-Developmental Disability (NDD)

### Objectives Of The Study

The study described herein was designed with the following

objectives

1. To develop an International Classification of Functioning, disability and Health (ICF) based checklist for disability in children with Neurodevelopmental Disability (NDD).
2. To validate the ICF based checklist developed by this researcher for disability in children with NDD.
3. To compare the ICF based checklist with the other gold standard scales like Neurodevelopmental Assessment using Child behaviour checklist (CBCL), Gessell Developmental Schedule (GDS) and Vineland Social Maturity Scale (VSMS).
4. To describe and compare disability in the cases and controls.
5. To compare functional status and disablement in children with Neurodevelopmental disability.

#### Statement Of The Problem

Disability in children with neurodevelopmental disability: Development and Validation of ICF based assessment checklist.

#### Hypothesis:

The children with autism spectrum disorder will have 3 times more disability than the other forms of neurodevelopmental disability.

#### Setting

The Institute of Neurological Sciences department, Voluntary Health Services Multi Specialty Hospital, Chennai (affiliated to The Tamil Nadu Dr MGR Medical University, Chennai).

#### Subjects

The subjects were drawn from an ongoing collaborative health care projects in association with Spastic Society of Tamilnadu (SPASTN) and the special schools from Coimbatore, Tamilnadu. The clinician diagnosed case register was maintained; children from the special school with neurodevelopmental disability were identified and assigned as experimental group and the children from the mainstream school without the neurodevelopmental disability as control group.

#### Sampling Criteria

Purposive sampling technique was employed to recruit 300 children from the Special schools and Rehabilitation centre and 120 children from normal mainstream school. In the second stage, children with NDD were grouped based on their conditions in 5 groups (Autism, Cerebral Palsy, Down's Syndrome, Learning Disability and Mental Retardation) with 60 children in each group.

#### Inclusion Criteria

All children aged between 0 to 14 years who were clinician diagnosed neurodevelopmental disability based on the standards of medical care were assigned as case group. Those who fulfilled the criteria and whose parents consented for their child to take part were recruited in this study. Children who were clinician diagnosed as normal without any neurodevelopmental disability were assigned as control group.

#### Exclusion Criteria

- Aged above 14 years.
- Multiple disabilities with the visual and hearing impairment and cardiac problems.
- All other types of associated co-morbid disease and disability were excluded.

#### Sample Size

With power calculation and analysis based on the prevalence rate of NDD as 15%, it was estimated to have 300 as cases and 120 as control (normal) with 80% power and 5% significance.

#### Sampling Technique

Purposive sampling technique was used to recruit the

samples and was used to categorize the sample into cases with NDD and control (Normal).

#### STUDY DESIGN:

Case - Control Study.

#### Measures

- International Classification of Functioning (ICF) – Neuro-Developmental Disability (NDD).
- Child Behaviour Check List (CBCL).
- Gessel Developmental Schedules (GDS).
- Vineland Social Maturity Scale (VSMS).

#### Ethical Issues

The Voluntary Health Services Institutional Review Board had approved this study and ethical clearance certificate was submitted to The Tamilnadu Dr MGR Medical University prior to commencing the study.

#### Consent

Parents of children completed the Informed consent form after being duly briefed by this investigator. The information was verbally reiterated by the investigator in the local language (Tamil), and the information sheet (in Tamil) (Copy attached in appendices section) was given to the subjects and any doubts were addressed. All the subjects completed and signed consent forms in the presence of the investigator, and these were witnessed by another person an accompanying relative/friend/care giver/teacher of the children. They were informed that non participation in the study would in no way affect their clinical care, so that the consent once given can be withdrawn at any point of time without assigning any reason.

#### Protocols And Procedures

##### Stage I: Development Of ICF Based Checklist For NDD

Developed a scale for NDD based on ICF, by consensus process integrating evidence from preliminary studies including Delphi exercise, a systematic review, focus group discussions, in-depth interviews and empirical data collection. After training in the ICF and based on preliminary studies relevant ICF categories were identified by formal consensus process by experts from different background.

The expert team consisted of 3 physical therapists, 3 neurologist, 2 psychologist, 2 nurses and 1 social worker. The comprehensive ICF-CY core set and the brief ICF-CY core set was used as base to develop an ICF based checklist for NDD. Identification of the most typical and relevant categories of the ICF for children with NDD was done. The expert survey using the Delphi technique was conducted. Data were collected in 2 rounds and answers were linked to the ICF-CY and analyzed for degree of consensus. It was concluded that the list of ICF-CY categories that were considered relevant and typical for NDD by experts was created.

The ICF-CY based checklist was piloted in a sample of 30. The Delphi consensus process was used once again to modify the ICF-CY based checklist for NDD.

##### Stage II: Data Collection

Responders were contacted by the researcher, and an appointment arranged for the assessment. Information sheets and / or oral instructions outlining the nature and purpose of the proposed study were given in the local language (Tamil).

The assessment began with an explanation about the study, formal completion of informed consent procedures and brief review and clarification of records. After obtaining the informed consent, the participants were assessed with the following scales using Child Behavior Check List (CBCL), Gessell Developmental Schedule (GDS) and Vineland Social Maturity Scale (VSMS) and ICF based checklist for NDD. Children were assigned as cases with neurodevelopmental disability and the control (normal) group. The records of children identified and were scrutinized and assigned

manually by the researcher.

Children with neurodevelopmental disability (NDD) were also assessed by an expert for analyzing inter-rater reliability and followed up for reassessment after a month for analyzing the intra-rater reliability.

Normal children without the neurodevelopmental disability who consented to take part in the study were assigned as control.

There were 6 dropouts and non-responders in this study. The investigator remained blinded to the results of all the screening instruments during this process.

**Statistical Methods**

The statistical analysis was done using SPSS (IBM v.20 IL, CH). Descriptive statistics included means, standard deviations (SD), variance, and range. Chi-square tests for categorical variables and T-test for continuous variables carried out to compare ICF data with other comparable measures. Instrument was analyzed for internal consistency, reliability (using Cronbach's  $\alpha$ ). Multivariate analysis of variance was used to develop predictive statistical models for Neurodevelopmental disability.

**DISCUSSION**

In neurodevelopmental disorders like Down's syndrome, Cerebral Palsy somatic symptoms and their behavioral correlate, e.g., changes in energy and activity levels sleep and appetite changes and social withdrawal is suggestive of affective disorders<sup>37</sup>.

Regression to increased dependency, psychomotor agitation, and increased irritability, worsening of already existing behavioral problems, aggressive and self-injurious behavior, reduced communication and social isolation are more common among people with intellectual disability<sup>38</sup>.

Elimination and pervasive developmental disorders were found to be most frequent and self-injurious behavior disorders were most severe<sup>39</sup>. Previous studies reported that individuals with autism will have either co-morbid mental retardation<sup>3</sup> or atypical cognitive processes<sup>40</sup>.

In our study we have found that nearly 80% of all the children with neurodevelopmental disorders demonstrate Autistic trait by using Indian scale for assessment of Autism. It has been found that the children with autism spectrum disorder have 3 times more disability than other form of NDD. Overall, these data underline the importance of a comprehensive instrument which can measure the burden of neuro disability among children.

Our study shows that the ICF checklist developed by this researcher for NDD has good internal consistency (Cronbach's  $\alpha = 0.839$ ). However, these results are subject to interpretation and must be treated with a degree of caution.

The ICF NDD checklist's concurrent validity established by 0.854 with CBCL which measures for children's emotional, behavioral and social aspects of life. There is a significant concurrent validity has been seen with VSMS at -0.548, which assess personal and social skills pertaining to individuals from birth to 18 years, however it lacks an important parameter like environmental factor which is an integral part of ICF and also of ICF NDD checklist. While comparing with GDS we found that there is a significant but relatively weak correlation. Looking at sub-domains, GDS mainly focused upon behavioral aspects while body structure and environmental factors are being neglected. On the similar ground, the concurrent validity between GDS and CBCL has been found weak in other studies.

Though it has been validated on 300 children with Neuro-

Developmental Disability (NDD) and 120 children without Neuro-Developmental Disability in this study and compared with gold standard scales, it requires to be tested on a larger population of children with NDD globally, with the culture specific modification where required.

**SUMMARY AND CONCLUSION**

A culturally relevant and valid instrument for Neurodevelopmental disability based on World Health Organization – International Classification of Functioning for Child and Youth (WHO-ICF-CY) has been developed, which assesses children with neurodevelopmental disorders in detail in these domains of disability, namely body function, body structure, activity and participation and environmental factors.

The instrument has been demonstrated to have good psychometric properties, with consistently high internal consistency scores. On being analyzed for inter-rater and intra-rater consistency, the positive correlation was found statistically significant.

We also proved our hypothesis, that state that “the children with autism spectrum disorder will have 3 times more disability than the other forms of neurodevelopmental disability”

This study has shown that a considerable burden of disability exists in neuro-developmental disability, both in pilot study and in the main study. Importantly, the study has demonstrated unequivocally that children with neurodevelopmental disability have a significant burden of disability in the community.

It has probably been the first time that we have compared a range of measures of functions and disability in neurodevelopmental disability, specific in a population. Examining the results it becomes apparent that developed ICF checklist for neurodevelopmental disability scale performed well when compared with established gold standards like Child Behavioral Checklist(CBCL), Gesell Developmental Schedules (GDS) and Vineland Social Maturity Scale (VSMS).

This instrument has shown itself to be good at assessing health and disability specific to neurodevelopmental disability. It is not surprising therefore that in a population of individuals with neurodevelopmental disability, it outperforms the other scales.

Although intending to be a framework of guidelines for the assessment of disability and attempt to bring uniformity to disability diagnosis across the globe, criteria such as these, have perhaps due to their specific nature, achieved exalted status in clinical and epidemiological research, and are relied upon to discriminate disability cases from non-cases.

The ICF checklist of neurodevelopmental disability criteria-based measure of disability is the more relevant and straightforward. It is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation.

The study concluded that list of ICF categories that are considered relevant and typical for neurodevelopmental disability conditions by experts were created. This was an important step towards identifying ICF Core Sets for children with neurodevelopmental problems.

However, this ideal of criteria-based diagnosis does in several situations leave much to be desired. Trans-cultural settings where conventional rules may fail to apply are one

example.

The ICF, designed as a common language for multi-disciplinary use, is also a very helpful framework for defining the core competence for the physical therapy profession. This study was to identify ICF categories that describe the most relevant and common problems in children managed by physical therapists in acute, rehabilitation, and community health care settings.

The ICF is a universal and inclusive platform for the understanding of health and disability and a comprehensive classification system for describing functioning. It was proposed to integrate the ICF and the Guide to Physical Therapist Practice to facilitate clinical documentation by physical therapists.

Further studies that prospectively examine the developed scale, namely ICF NDD against other gold standard measures can be done before the instrument can be adopted for widespread application. It is clear though with the limited evidence presented herein that the ICF NDD may well be a useful and valid measure for the assessment of disability in children with neurodevelopmental disability.

Our finding of considerable disability in this population, highlights the importance of Standard protocols for the identification and referral to disability health professionals

**Disability Health Training For Caregivers**

We believe that our data and the prospective use of this developed ICF NDD scale to assess disability in these settings; will help in identifying more children with hitherto unidentified disability; aid in assessing the need for specialist disability health services for children with neurodevelopmental disability, the disabled and those in residential care in particular; aid in the rehabilitation process; provide data in support of the need for improved disabled health service provision in these settings for all stakeholders including government policy makers and perhaps most importantly improve outcome for children with special needs.

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