

Development of severity Rating scale for children with Autism Spectrum Disorders

by Shyamala K.c.

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PROJECT PROPOSAL

PART- A

1.0 **Title of the project: Development of severity Rating scale for children with Autism Spectrum Disorders**

Area of Research: Speech, Language, hearing

1.1 **Principal investigator** : Dr. Shyamala K.C

1.2 **Principal co-investigator** : Dr. Vasantha Lakshmi M S

1.3 **Collaborating institution** : Nil

1.4 **Total Grants required** : 4,50,000 (four lakhs fifty thousand)

1.5 **Duration of the project** : 1 year

2.0 **Project Summary :**

A severity rating scale would be developed to assess the functioning level of a large group of children with autism spectrum disorders. It would assist the speech language pathologists in identifying the extent of the disorder, monitoring their independency level in carrying out day to day activities during the course of intervention & to envisage the prognosis. With the help of the developed severity rating scale, their progress can be tracked with an aim of improving their quality of life.

Introduction

As reported in the literature, among children who are diagnosed with ASD, most of them were found to be mildly disabled whereas some of them were severely disabled. Children

with ASD whose severity was reported to be mild may develop speech and language skills, social interaction skills and life skills at an early age and they will be able to function with minimal assistance, whereas those whose severity was reported to be severe may develop speech and language skills, social interaction skills and life skills slowly and require constant support in performing the functional activities in real life situations. On the western forefront, the frequently used measures for assessing the severity of ASD are ⁴ Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1994) and Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999). Both the measures were reported to be a well-established, professional rated measures and aimed to quantitatively measure the severity level ¹⁰ of children with Autism Spectrum Disorders. In comparison to DSM IV criteria for autism spectrum disorders, the above mentioned tools were found to assess the symptoms in ASD that are more physical and health related in nature but the DSM IV criteria for ASDs assesses only the presence of triad characteristics of autism. In Indian context, the differential diagnosis checklist for autism spectrum disorders aimed to document the overall severity of ASD based on the health professionals' subjective perception but it does not use any rating scale to assess the severity of their functioning in different aspects. Thus an attempt should be made to develop a severity rating scale for assessing the severity level of each of their functional skills.

Need for the study

A severity rating scale would be developed to assess the severity level of children with autism spectrum disorders. This would be a prognostic indicator and it would assist the

speech language pathologists in assessing their independency level in carrying out day to day activities during the course of intervention. With the help of the developed severity rating scale, their progress can be tracked with an aim of improving their quality of life.

Aim of the Study

To develop and implement the severity rating scale in Indian context ⁵ for pre-school children with Autism Spectrum Disorders

Objectives

- To formulate the severity rating scale for assessing the severity level of Indian pre-school children with autism
- To investigate the feasibility of administering the developed severity rating scale by assessing their severity level in several domains such as Speech and Language skills, Social Communication skills, Cognitive Functions, Sensory Functions and Physical behavior etc and predicting their prognosis.

Method

Participants

N number of children diagnosed with Autism Spectrum Disorders will be considered for the study.

Inclusion criteria

Children who are diagnosed with Autism / PDD-NOS / Asperger syndrome will be considered for the study. Their diagnosis should be made by using the standardized

test named Differential diagnosis checklist for Autism Spectrum Disorders (DDC-ASD) (Chengappa et al. 2007). The participants should be in the age range of 2-8 years. They can either be mainstreamed or schooled or unschooled.

Exclusion criteria

Children who are diagnosed to have comorbid disorders linked with Autism/PDD-NOS/Asperger syndrome and those who are diagnosed with Rett's disorder / Childhood disintegrated disorder will be excluded from the study.

The study will be carried out in phases

Phase 1- Development of the severity rating scale

The developed severity rating scale will include several domains namely Speech and Language skills, Social Communication skills, Cognitive Functions, Sensory Functions and Physical behavior etc . On the whole, this tool will comprise of hundred items where each domain will include twenty items. These 100 items belonging to those domains will be adapted from ASD assessment tools such as Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1988), Autism Diagnostic Observation Schedule (Lord, Rutter, Dilavore&Risi, 2001), Autism Diagnostic Interview - Revised (Rutter, Le Counter & Lord, 2003) and Autism Treatment Evaluation Checklist (Rimland & Edelson, 1999). The items which are sensitive enough to assess the severity level of children with Autism Spectrum Disorders will be adapted from the above mentioned ASD assessment tools.

Phase 2 – Validation of the developed severity rating scale

The five master's degree holders in ⁷ speech language pathology will be asked to rate the adapted items for the process of validation. The judges will be asked to rate these adapted items with respect to its sensitivity in assessing the severity level of children with ASDs. They will be asked to respond by marking each item as 'Least sensitive', 'Fairly sensitive' and 'Most sensitive'. The items with 60% agreement (3 out of 5) between the five judges will be included in the inventory. The items rated as 'Fairly sensitive' and 'Not sensitive' by three out of five judges will be excluded from the tool.

Phase 3 – Framing a scoring scale for the five domains

For assessing the participants' severity level, a five point rating scale will be developed to score each item where

³
0 - No problem

1 - Indicates mild problem

2 - Indicates moderate problem

3 - Indicates severe problem

4 - Indicates profound problem

The scale will be administered to N number of ASD children. All the items from each domain will be rated on this above mentioned five point rating scale. With respect to the average domain scores, cut off scores will be given to discriminate severity levels.

Phase 4 -Administering the developed severity rating scale for measuring inter-rater reliability

The developed severity rating scale will be administered by two master's degree holders in Speech Language Pathology on one fifth of the sample within two weeks (1 week for each) and the Inter-rater reliability will be assessed. Both the raters will be informed about the guidelines to administer the developed severity rating scale for children with ASDs (including the scoring guidelines).

Phase 5 – Feasibility of administering the developed severity rating scale in clinical set-up (Sensitivity of the Severity rating scale)

The developed severity rating scale will be ⁶ administered to a different group of 20 ASD children with Autism/ PDD-NOS/Asperger syndrome (2 to 8 years age group) for assessing their severity level in the domains namely Speech and Language skills, Social Communication skills, Cognitive Functions, Sensory Functions and Physical behavior etc. Sensitivity value of the rating scale will be calculated. This is hoped to assist SLPs dealing with ASD in predicting their prognosis.

Implications of the study:

1. This severity rating scale will assist the SLPs in predicting the prognosis of the children with ASD.
2. This will help in assessing and profiling the children with ASD with respect to various developmental domains.
3. This will assist tracking progress with intervention in children with ASD.

Development of severity Rating scale for children with Autism Spectrum Disorders

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9 Goin-Kochel, Robin P., Barbara J. Myers, Dawn R. Hendricks, Staci E. Carr, and Shirley B. Wiley. "Early Responsiveness to Intensive Behavioural Intervention Predicts Outcomes Among Preschool Children with Autism", International Journal of Disability Development and Education, 2007.
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10 Payakachat, Nalin, J Mick Tilford, Erica Kovacs, and Karen Kuhlthau. "Autism spectrum disorders: a review of measures for clinical, health services and cost-effectiveness applications", Expert Review of Pharmacoeconomics & Outcomes Research, 2012.
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