An ICF-CY based Functional Assessment Questionnaire for Pre-school Children with Autism in an Indian Context

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May, 2016

CERTIFICATE

This is to certify that the dissertation entitled "An ICF-CY based Functional Assessment Questionnaire for pre-school children with Autism in an Indian Context" is the bonafide work submitted in part fulfillment for the degree of Master of Science (Speech-Language Pathology) of the student (Registration No.14SLP012). This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled ***An ICF-CY based Functional Assessment Questionnaire for pre-school children with Autism in an Indian context*** is the result of my own study under the guidance of Prof. Shyamala K.C., professor in Language Pathology, Department of SLP, All India Institute of Speech and Hearing, Mysore, and has not submitted earlier in any other University for the award of any Diploma or Degree.

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CHAPTER I

INTRODUCTION

The conventional Autism Spectrum Disorders' (ASD) assessment tools namely Autism Diagnostic Observation Schedule (Lord, Rutter, Di Lavore & Risi, 2001), Autism Diagnostic Interview - Revised (Rutter, Le Couteur & Lord, 2003), Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1988) and Diagnostic and statistical Manual of Mental Disorders IV (American Psychiatric Association 1994) etc identify the main areas of functional deficits seen in children with Autism Spectrum Disorder (ASD) as communication, social interaction and restricted, repetitive and stereotyped patterns of behaviors, interests and activities. Currently, they are researched upon in accordance with ICF-CY framework. Their functional characteristics are documented in a universal language and classified according to four domains namely Body functions, Activities, participation and Environmental factors.

Castro, Ferreira, Dababnah and Pinto, (2013) had linked the items of each of the diagnostic tools namely Autism Diagnostic Inventory -Revised, Autism Diagnostic Observation Schedule and Childhood Autism Rating Scale with ICF-CY functional framework and found a strong agreement between the mentioned assessment tools and ICF-CY. Based on the linking process, the results revealed that these ASD measurements provide limited information on specific functional aspects and they failed to measure the influence of specific environmental factors on participation and account the specific and individualized characteristics of the child's performance in day to day situations in a universal language that can be understood among the interdisciplinary team members (Castro et al. 2013).

Provost, Lopez and Heimerl, (2007) reported that among children with ASD, diversity in the development was observed. These mentioned tools mask the functional disparities within the same diagnosis and this imposes challenge on intervening children with ASD. According to World Health Organization, these ASD assessment tools may assist the speech language pathologists in confirming the diagnosis but the structured nature of these tools restrict the health professionals to individualize the intervention process (Etscheidt 2003).

Mottron, Dawson and Soulieres, (2009) reported that these ASD assessment tools document only the deficits observed in children with Autism but they fail to account for the strengths which influence their overall functioning. Thus, these measurements do not implement a holistic approach towards disability. This is also true of our context and tools such as Differential diagnosis checklist for Autism Spectrum Disorders (DDC-ASD) (Chengappa, Vijayashree & Shastty, 2007).

Hence, the disadvantages of these traditional ASD assessment tools led to the usage of a comprehensive tool that is ICF-CY that allows the speech language pathologists to set individualized intervention programs and promote child' s functional independency level and social participation.

The ICF-CY (World Health Organization 2007) derived from ICF, comprised of two parts namely functioning and disability and contextual factors. Functioning of part 1 includes body functions/structures, activities and participation whereas disability of part 1 includes impairments in body functions/structures, activity limitations and participation restrictions. The second part which is the contextual factors includes environmental and

personal factors. The scoring scale relevant to each ICF-CY domain was developed by World Health Organization (WHO). The scores obtained from the scoring scale indicate the severity level of the problem. For each domain, a code was given where b indicates body functions, d indicates activities and participation and e indicates environmental factors. The ICF-CY is considered to be a biopsychosocial model (Bickenbach, Chatterji , Badley & Üstün, 1999; World Health Organization 2007) where bio refers to body functioning, social stands for participation in real life situations and psycho refers to the link between body functioning and participation and this link describes the child' s ability to perform activities (Bjorck-Akesson et al. 2010).

However, the International Classification of Functioning Health and Disability for Children and Youth (ICF-CY) provides a universal language for documenting and assessing the developing children with impairment of body function (impairment in physiological functions of body systems), activity limitation (difficulty to execute tasks) and participation restriction (unable to involve in real life situations) (World Health Organization 2007). It also measures the developing child's ability and disability associated with the diagnosis. Rather than identifying children based on diagnostic labels, ICF-CY identifies children on the basis of functional profile (Baron & Linden, 2008). Thus, ICF-CY must be used as a classification but not as a diagnostic tool.

Gan, Tung, Yeh and Wang, (2013) found that their developed ICF-CY based parent report questionnaire for autism documents the functional profile of pre-school children with autism in a common language that can be comprehended among the health professionals of various disciplines. Their participants' functional performances were assessed in four domains namely body functions, activities, participation and

environmental factors. Personal factors belonging to the second part of ICF-CY was not included in their developed questionnaire. They also reported that their developed ICF-CY based parent report questionnaire for autism supplements the traditional ASD assessment tools. The uniqueness of each child with autism with respect to functioning aspects can be recognized by using this questionnaire. The scoring scale used in this questionnaire indicates the severity of impairment. The intervention outcomes and the developmental changes in functional aspects for each child with autism can be tracked with the help of this scoring scale. McCormack, McLeod, Harrison and McAllister, (2010) reported that by asking questions from ICF-CY questionnaire to the parents of children with autism, the parents would give an insight on the child's performance in different contexts. Based on the functional profile obtained from this questionnaire, individualized intervention goals focusing on improving his capabilities to execute the tasks, provision of environmental facilitators and removal of environmental barriers can be set.

Need for the Study

To overcome the pitfalls of traditional ASD assessment tools, an ICF-CY based questionnaire was developed for autistic pre-school children. It provides a universal framework to assess their specific functional characteristics within the triad deficit areas, the developmental aspects of each child functioning in real life situations and also the impact of specific environmental factors on participation. Thus it would help in classifying the disability in terms of four domains body functions, activities, participation and environmental factors. With the help of qualifiers, the speech language pathologists can rate the severity of the impairment within the four domains. Since it is compatible

with conventional ASD diagnostic tools, it can identify the uniqueness of each child with respect to functioning aspects. It also helps in setting goals in a common language focusing on reducing the severity level of the problem in body functions domain, improving their independency level in executing the tasks in real life situations, provision of environmental facilitators and removal of environmental barriers that interferes with the child's ability to communicate in their home and communities (Rosenbaum & Stewart, 2004). Thus it is helpful in implementing an individualized intervention program. Moreover, it can be used to chart their progress and developmental changes in functional aspects with the help of the qualifiers.

At present, there is no literature to support the use of ICF-CY based questionnaire for Pre-school children with autism in Indian context. An attempt would be made to suitably modify the Taiwanese based ICF-CY questionnaire for Autism (Gan et al. 2013).

AIM OF THE STUDY

To modify the ICF-CY based parent report questionnaire for Children with Autism developed by Gan et al. (2013) and implement the modified version of ICF-CY based parent report questionnaire in Indian context for pre-school children with Autism.

OBJECTIVES

1) To adapt and develop an ICF-CY based assessment tool for assessing the functional abilities of Pre-school children with Autism in Indian context

2) To assess the functional level of Pre-school children with Autism in 4 domains namely Body Functions, Activities, Participation and Environmental Factors using the modified ICF-CY based parent report questionnaire for Autism

3) To investigate whether the subjects' participation is influenced either by their problems in Body Functions or Environmental Factors or both

CHAPTER II

REVIEW OF LITERATURE

The International Classification of Functioning, Disability and Health - Child and Youth version (ICF-CY) was developed to be used as a universal platform for the assessment of children's abilities and disabilities (World Health Organization 2007). It assists the health professionals to code the developmental functional changes and also to set intervention goals for children with any disabilities. It was proved that ICF-CY aimed to give an overview of one's own learning abilities and also the influence of environmental factors on one's own functionality.

Applicability of ICF-CY for documenting the functional performance and environment of children with disabilities

On reviewing four empirical studies, Nina Klang (2012) investigated the correlation of components and categories in ICF-CY with the child's functioning and environment and also the feasibility of using ICF-CY among health professionals working with children with disabilities.

On reviewing the first and second studies, the author had found discrepancies in ratings of items in the questionnaire in accordance to the performance qualifier in Activities and Participation component. Nina Klang (2012) assumed that these discrepancies may be justified by the context in which ratings were made and also by perceptions and expectations of the proponents who made the ratings. The results of the review of these two studies had pointed out the challenges imposed in establishing a common measure of the performance qualifier. The second and third studies were reviewed to find out

whether the sub-domains in the body functions and activities and participation components were interrelated or not. On reviewing these two studies, the author had reported that the categories in the body functions and activities and participation components were interconnected.

In the second study, professionals had documented the advantages and challenges imposed in the use of the ICF-CY questionnaire and had also recommended required modifications to the ICF-CY questionnaire. The third study had specified challenges in profiling the family situation and children's psychosocial environment in the environmental factors component. And lastly, the fourth study had mentioned that after in-service training, the speech language pathologists had accounted the children's functional performance more accurately and in a detailed manner.

Therefore this review study had implicated a need for integrated use of the sub-domains from all the domains belonging to ICF-CY.

Ibragimova, Granlund and Bjorck-Akesson, (2009) investigated the practicality of assessing the Swedish children with disability by using the ICF-CY questionnaires. The ICF-CY questionnaires had included items in accordance to ICF-CY categories following the classification framework, questions about its practicality and also a column for elucidating the opinions.

Four types of questionnaires containing 90 to 102 items were used for children in different age groups (less than 3, 3-6 years, 7-12 years, 13 years and greater than 13 years). A group of professionals such as 47 special educators, 43 physiotherapists and 20 occupational therapists had administered the questionnaires on 130 children (one month

to 19 years). Among 130 children, the commonly made diagnoses were cerebral palsy, autism and developmental disorders.

The results revealed that the items in the ICF-CY questionnaires did not pertain to the structure mentioned in the ICF-CY. With regard to component level, items belonging to Body Functions and Activities and Participation had built common groups. With regard to chapter level, though the questionnaire items were not classified pertaining to the chapter structure as mentioned in ICF-CY, it had grouped according to contextually and functionally defined factors.

The authors had reported that there was a significant disparity in professional's ratings among the children younger than 3 and 3-6 and 7-12 year old children especially in four chapters of Activities and Participation (namely, learning and applying knowledge, chapter-3 communication, mobility and major life areas). This disparity was justified by stating that disparities in the performance of children of different age range may be easier to assess the items based on performance qualifier which was used in Activities and participation domain when compared to assessing items based on body functions or environmental factors components. Another justification is that the observed significant disparity may be related to professionals' expectations of children's functional performance.

Therefore, Ibragimova et al. (2009) reported that majority of the speech language pathologists had found that the evaluation can be done by using ICF-CY questionnaires in a clinical set up where there is interdisciplinary organization.

Comparison of content with International Classification of Functioning, Disability and Health child and youth version to other various ASD traditional instruments namely ADI-R, ADOS and CARS and International Classification of Functioning, Disability and Health child and youth version functionality and code selection in specific clinical settings were performed and reported in the literature.

International Classification of Functioning, Disability and Health child and youth version functionality and code selection in specific clinical settings

The applicability of International Classification of Functioning, Disability and Health child and youth version (ICF-CY) activities and participation d codes to children and young people with disabilities resulting from disorders of the spine, muscles, sensory organs, and central nervous system in clinical practise was evaluated by Illum and Gradel, (2015). The core data set of ICF-CY codes comprises of second, third and fourth level d codes. Totally, 57 d codes for activities and participation were selected. The selected codes were intended to describe the functional performance of 332 children (aged 1 to 15 years) in activities of daily living.

As a result of Rasch analysis, the 57 d codes were lessened to 39 and the graphical data for disability measures was homologous to the clinical assumptions across the overall population of 332 subjects. With relevance to the person-code maps for activities and participation d codes, children with severe and complex disabilities were positioned at the upper endpoint of the disability variable and those with minor motor problems were positioned at the lower endpoint. Illum et al. (2015) reported that Position on the

continuum for the disability variable corresponded well with the complexity and severity of the factors measured by specific activities and participation d codes.

In response to the concern that whether activities and participation d codes behaved differently across diagnoses, ages, and genders, differential item functioning seemed fair across most items for all the mentioned child characteristics. The consistency was found to be least satisfactory across age, with t values close to 2 or - 2 for few items. Age has not been mentioned in ICF-CY version since International Classification of Functioning, Disability and Health child and youth version codes were seen as universal across age.

In conclusion, it is believed that the International Classification of Functioning, Disability and Health child and youth version d code data intends to provide a uniform measure of severity level of the disability among children across various diagnoses, age, and genders.

In another study, where the application of the activities and participation component of the ICF-CY as a framework for exploring the speech language pathologists and parents' perceived impact of speech impairment in pre-school children was investigated by McCormack, McLeod, Harrison and McAllister, (2010).

The ICF-CY questionnaire comprised of 32 items which were chosen from six domains such as Learning and applying knowledge, General tasks and demands, Communication, Domestic life, Interpersonal interactions and relationships and Community, social and civic life. Ten items were selected from Learning and applying knowledge, 5 items were selected from General tasks and demands, 8 items were selected from communication, one item from domestic life, 6 items form Interpersonal interactions and relationships and two items from community, social and civic life. The items from three domains such as

mobility, self-care and major life areas were excluded from the questionnaire. The selected items correspond to the tasks relevant to 4 -5 year old children. The developed ICF-CY questionnaire was given to 205 speech language pathologists and 85 parents of 4-5 year old pre-school children with speech impairment.

The factor analysis of the parent's data indicated five coherent factors such as Verbal communication (e.g., Conversation, Speaking), Advanced learning (e.g., Learning to read/write), Interpersonal interactions (e.g., Relating with strangers, Informal social relationships), Basic learning (e.g., Copying, Rehearsing), Applied learning and general tasks (e.g., Focusing attention, Handling stress) whereas the SLP data indicated six coherent factors with moderate to high inter-rater reliability. The six identified factors by SLP s are Verbal communication (e.g., Conversation, Speaking), Advanced learning (e.g., Learning to read/write), Interpersonal interactions (e.g., Relating with strangers, Informal social relationships), Basic learning (e.g., Copying, Rehearsing), Applied learning and general tasks (e.g., Focusing attention, Handling stress), and Non-verbal communication.

Verbal communication coherent factor

Though the parents and SLPs indicated that verbal communication as the most difficult factor for their children with speech impairment, significant difference was obtained in the degree of impact recognized by both the groups. This difference was attributed to the difference in the perception of their child's speech impairment by both the groups. The two most items belonging to verbal communication factor which were considered by the parents as being difficult were conversation and speaking whereas the SLPs had

recognized five items such as Conversation, Speaking, Discussion, and Using communication devices as being "often" difficult for children with speech impairment.

Advanced learning coherent factor

With relevance to the parents' and SLPs' mean factor scores for Advanced learning factor, both the groups had rated this factor as being the second most impacted factor for their children with speech impairment. Half the SLPs had rated two items of this factor such as learning to read and learning to write as being "often" affected by their children's speech impairment. 25.6. % of the parents had rated learning to write item as being difficult for their children as a consequence to their speech impairment whereas 16.3% of the parents had rated the learning to read item as being difficult.

Applying learning and general tasks factor coherent factor

The factor scores for both parents and SLPs indicated that they did not consider the Applying learning and general tasks factor as being most effortful for their children with speech impairment. The SLPs had rated the difficulties with this mentioned factor as the fifth most affected area for their children with speech impairment whereas the parents had rated it as third. With relevance to this factor, the items which are frequently recognized by the parents as being affected by their child's speech impairment are Focusing attention (22.1%), Managing one's own behavior (17.4%), Handling stress and other psychosocial demands (17.4%), and Undertaking multiple tasks (15.1%). 16.1% of the SLPs had indicated that handling stress item had impacted their children with speech impairment. Few SLPs had considered items such as Managing behavior, Focusing

attention, and Undertaking multiple tasks as often being impacted by children with speech impairment.

Interpersonal Interactions coherent factor

The SLPs had rated the interpersonal interactions factor as being the third most affected area for children with speech impairment because they felt that this factor was considered as the "sometimes- often" effortful for children with speech impairment. The parents had rated the interpersonal interactions factor as being the fifth most impacted for children with speech impairment because they found that this factor was occasionally difficult for their children with speech impairment. SLPs indicated that children with speech impairment faced difficulties with formal relationships and informal social relationships. Both the groups SLPs and parents had commonly recognized that their children with speech impairment had problems in relating with strangers.

Basic learning coherent factor

Both the groups, parents and SLPs had considered the Basic learning factor as one of the least difficult factors for their children with speech impairment. With relevance to the items of this factor, the parents did not perceive them as an impact for their children with speech impairment whereas SLPs had considered those items as "sometimes-often" difficult.

Non-verbal communication coherent factor

The mean factor score for non-verbal communication was the lowest among all the factors and it showed that this factor was recognized as the least impacted area for

children with speech impairment. The factor score for non-verbal communication was computed only for SLPs. The items of this factor were rated as the least frequently recognized by both the groups.

Hence, McCormack, McLeod, Harrison and McAllister, (2010) concluded that ICF-CY Activities and Participation component is a useful framework for considering the breadth of activities that may be impacted by speech impairment in childhood.

Since several authors have profiled the abilities and disabilities of children with Cerebral palsy and Developmental disorders based on ICF-CY framework, Gan, Tung, Yeh, and Wang, (2013) had attempted to develop an International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY) parent based questionnaire for preschool children with autism.

International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY) based assessment tool for children with autism

This questionnaire comprised of 118 items from the body functions, activities, participation and environmental domains. The Body functions domain comprised of 28 items and four categories namely, mental functions, sensory functions, pain/movement-related functions and voice/ speech functions. The Activities domain comprised of 41 items and included five categories such as learning and applying knowledge, general task and demands, communicating-receiving, mobility and self-care. The Participation domain comprised of 36 items and included three categories such as communicating-conversation, interpersonal interactions and relationships and domestic life/major life areas. The environmental domain comprised of 13 items and included products and

technology, support and relationships, and attitudes. Five point rating scale will be used for these four domains.

The rating scale used for impairment of body functions reflects the severity of the problem, where score 0 denotes complete problem and 4 denotes no problem. The rating scale used for Activities domain reflects the independency level (capacity) of the child in executing a task where score 0 denotes greatest difficulty and 4 denotes no difficulty. The rating scale used for participation domain indicates the extent of support and duration of assistance required for the child to participate or execute or perform the given task in real life situations where 0 denotes independence and 4 denotes total physical dependence. The last domain which is the environmental domain utilizes the five point rating scale to denote whether the item mentioned in the questionnaire is a barrier (−2 to −1), a facilitator (+1 to +2), or has no influence (0) on the child's participation in relevant life functions.

The study was conducted in two parts.

In the first part, the inter-rater reliability of the ICF-CY based parent report questionnaire for pre-school children with autism was assessed by asking the 2 raters to administer the questionnaire to the same group of 26 pre-school children with autism twice within 2 weeks. Its results revealed that moderate to excellent agreement was found for most of the items in body functions (82.1%), activities (97.5%) and participation (97.1%) domains. Among the items in environmental domain, 46.2% of items in the environmental domain were found to have moderate agreement whereas 53.8% of the items were found to have poor agreement. The questionnaire had proved to be efficient in

profiling preschool children (3-6 years) with Autism functioning in domains such as Body Functions, Activities and Participation except Environmental Factors.

In second part of the study, the authors had used the parent based ICF-CY questionnaire to assess the functional performance of 136 preschool children (3-6 years) with Autism in four domains namely Body functions, Activity, Participation and Environmental factors.

They had found that the extent of impairment of Body Functions was lesser than the level of disability for the Activities and Participation domains. Among the four domains, the domain which was most difficult for these children was Participation domain. Because preschool children with autism required longer duration of support in conversation (namely, starting a conversation, sustaining a conversation and taking turns) and major life categories (such as helping prepare meals, shared cooperative play and engaging in structured activities in group settings).

In the Environmental Factors domain, the authors reported that health professionals, teachers and parents were considered to be the strong facilitators in influencing the behavior of the child with autism whereas the peers, neighbors and extended family members were found to be the weak facilitators. Among the items reflecting attitudes, they had found that the parent‘s distress for their child was associated with severity level of impairment, coping strategies and negative attitudes of the society.

Within the items of social communication, they had found that these preschool children with autism had difficulties in joint attention, acquiring syntax, comprehension of complex spoken language, acquiring information and engaging pretend play and shared

cooperative play. These results were in accordant with the functional characteristics of autism.

Thus, the authors proved that this developed the ICF-CY based parent report questionnaire would be beneficial for the speech language pathologists to profile the functional performance of pre-school children with autism.

Application of ICF-CY framework to determine the factors related to the participation of pre-school children with Autism

In continuation to the previous study Gan, Tung, Yeh, Chang and Wang, (2014) designed the structural equation modeling of factors associated with participation with respect to the data collected by using the ICF-CY based autism questionnaire. The test of the four second order measurement models ((body functions, activities, participation, and environmental domains) resulted in appropriate parameter estimates and fit indexes.

The **second order measurement model of body functions domain** comprised of four latent variables namely body functions, mental function, sensory functions and pain, voice and speech functions and among these four latent variables, the attention functions, sensation of body pain and speed of speech were found to have strongest prediction in each latent variable category.

The **second order measurement model of the activities domain** included five latent variables namely activities, learning and applying knowledge, general tasks and demands, communicating-receiving, and self-care and 14 observed variables. The only category which was not included in the model was mobility category. The highest predictor in

each latent variable category was acquiring language, following routines, speaking, dressing/washing oneself and learning and applying knowledge.

The **second order measurement model of the participation domain** comprised of four latent variables namely participation, conversation, interpersonal interactions and relationships, major life areas and among these four latent variables, starting a conversation, initiating social interaction, helping prepare meals and interpersonal interactions and relationships were considered as the strongest predictors in each latent variable category.

The **second order measurement model of the environment domain** included four latent variables such as environment, products and technology, support and relationships, and attitudes and the strongest predictors in each latent variable category were products for education, teacher support, teacher attitudes, support and relationships.

Based on the correlation analysis, moderate to high correlation was obtained between body functions versus activities and body functions versus participation and a poor to fair correlation was obtained between the categories of environmental factors versus activities and environmental factors versus participation. A high correlation was computed among the categories of activities and participation. Therefore, the difficulties on the activities or participation level faced by pre-school children with Autism were found to be influenced strongly by problems in one's own body functions and weakly by the environmental factors.

The structural equation model was constructed to identify the pathway diagram between body functions domain (e.g. mental functions, sensory functions and pain, voice and

speech functions), personal factors (e.g. age levels and educational placement) and activities domain correlating with participation domain in children with autism. The fourth domain namely environmental factor was not entered in this model. The overall fit of the constructed structural model was found to be adequate on standard fit index criteria. Gan et al. (2014) indicated that all the exogenous variables of body functions and personal factors accounted for 77% of the explained variance for activities and for participation by 71% of the children with autism. The findings of this current study revealed that the domain which had the strongest total effect on participation was activities.

Since the activities were shown to have a strong positive direct effect on participation, it was considered as the significant mediator between the exogenous variable correlates (mental functions, sensory functions and pain, voice and speech functions, age levels, educational placement) and participation. The total effect of association between exogenous variables (such as sensory functions and pain, voice and speech functions, age levels) and participation were found to be not significant, that is these factors were not directly related to the participation domain. Since the participation domain documents the level of functioning at body, person and societal levels and also the person's environmental factors, the results of this study provides critical information for parents, educators, and professionals on the components reflecting the participation of pre-school children with autism.

Moreover, these two studies supports that these 118 items from ICF-CY based questionnaire for autism represents the heterogeneity of functional disparities observed among children with autism in correspondence to ability and disability associated with it.

It was also said that these 118 items highlights the importance of ICF-CY as a framework to document a child with autism‘s functioning in all dimensions of life.

In comparison to the ICF-CY based questionnaire for Autism, the strengths and weaknesses of the western based ASD traditional assessment tools will be discussed below

Autism Diagnostic Interview- Revised (ADI-R) (Rutter et al. 2003)

It involves a structured based interview method and comprises of 93 items specifically designed for parents of pre-school children with ASDs. This interview based instrument aimed to get a detailed insight on the child’s developmental history and assesses three important ICD-10’s diagnostically relevant domains of functioning namely language/ communication, social interactions and restricted, repetitive and stereotyped behaviors and interests. The overall diagnostic algorithm provided by ADI-R helps the speech language pathologists in distinguishing children with autism from typically developing children. The ADI-R often complements the ADOS assessment measures (Castro et al. 2013).

Autism Diagnostic Observation Schedule (ADOS) (Lord et al. 2001)

A semi-structured standardized tool designed to evaluate pre-school children who are suspected to have Autism Spectrum Disorder and mainly, their communication skills, play skills, social interaction skills and also their imaginative skills of using the materials will be assessed by using this instrument. The overall diagnostic algorithm provided by ADOS will aid the speech language pathologists in distinguishing between children with autism, ASD and without ASD.

Childhood Autism Rating Scale (CARS) (Schopler et al. 1988)

A seven point behavioral rating scale designed to assess the level of characteristics of autism. This screening tool comprised of fifteen items. A score of 30 or above indicates the confirmation of autism diagnosis. It mainly assists the health professionals in distinguishing children with autism from children with other intellectual and developmental disorders. It also helps in categorizing the assessed behaviors from mild to moderate to severe. CARS was proved to be a highly reliable parent interview based screening tool (Dilalla & Rogers, 1994).

Unlike ICF-CY questionnaire for Autism (Gan et al. 2013), these tools mainly

1) Classify children based on diagnostic labels

2) View disability from a unidimensional perspective

3) Restrict the health professionals in identifying the facilitators which will facilitate the child to participate independently in real life situations

4) Do not assist in monitoring intervention outcomes

5) Focus only on the weaknesses faced by children with ASD

6) Do not identify the uniqueness in functionality among children with ASD

The literature reports few studies on the efficacy of the integrated use of ADI-R and ADOS. A study done by Risi et al. (2006) revealed that the integrated ADI-R and ADOS proposed criteria did not ameliorate the performance over the assessment tools ADI-R/ADOS when used alone. Thus, Autism Diagnostic Interview-Revised and Autism

Diagnostic Observation Schedule make independent, additive contributions to clinician's judgement that leads to a more consistent and rigorous application of diagnostic criteria.

Contrary to this study's finding, Le Couteur, Haden, Hammal, and McConachie, (2008) proved that the integrated use of ADI-R and ADOS have an interdependent effect in providing a greatest level of diagnostic clarity whereas, when either of these instruments administered alone, each would over or under rate the particular behaviors.

Only few studies on comparison of ADI-R with Childhood Autism Rating Scale (Pilowsky, Yirmiya, Shulman & Dover, 1998) were quoted in the literature. Saemundsen, Magnússon, Smári and Sigurdardóttir, (2003) reported that CARS assessment tool can classify more children with autism than ADI-R with respect to the comparison made based on the 30-point cutoff score on the CARS and the need to reach or exceed the cutoffs of the three domains of the ADI-R. Therefore, Saemundsen et al. (2003) stated that autism as defined by the three thresholds on the ADI-R seems to be more restrictive than the category of autism as defined by the CARS.

In comparison to the ICF-CY based questionnaire for Autism, the strengths and weaknesses of the Indian based traditional assessment tools will be discussed below:

Diagnostic Scale for Autism Spectrum Disorders (DSASD)

Chakravarti, (2002) developed Diagnostic Scale for Autism Spectrum Disorders (DSASD) to assess the severity of Autism Spectrum Disorders and also to document the peculiar characteristics observed in 2-7 year old children with ASD. The checklist comprised of four domains such as social, cognitive, behavioral and communication. The subtests of social domain included interpersonal interaction and play; the subtests of

behavioral domain included general behaviors, sensory behaviors, adaptive behaviors and motor behaviors and the subtests of communication included pre-linguistic skills, non-verbal communication and verbal communication. There were no subtests for cognitive domain. A five point rating scale was used to rate the questions of each domain. Depending on the scores of each domain, the severity of the impairment can be measured for each domain. This checklist can monitor the child's progress following intervention and also helps in setting intervention goals.

In comparison to ICF-CY questionnaire for Autism developed by Gan, et al. (2013), the DSASD focuses more on identifying the presence of critical characteristics in order to diagnose whether the child has ASD features or not whereas it seems to be less efficient in profiling the holistic view of the functional and linguistic abilities observed in children with ASD. It does not assess whether the support provided by the parents and relatives and their attitudes facilitates/hinders the child's functioning or not. Lastly, for all the questions in the checklist, it does not assess the level of difficulty since few questions required yes/no responses.

Differential diagnosis checklist for autism spectrum disorders (DDC-ASD)

Development of assessment tool for differential diagnosis of autism spectrum disorder (DDC-ASD) was developed by Shyamala et al. (2007). The checklist comprised of 9 domains such as development, regression, motor, behavior, physical/medical, sensory, intellectual, social and speech and language skills. This checklist assesses the characteristic symptoms observed among children with Autism, Asperger syndrome, Rett's disorder and Childhood disintegrated disorder. The responses recorded for each

question were present or absent. It mainly differentially diagnoses children with ASD and also assesses the severity of the ASDs. Similar to DSASD, DDC-ASD also monitors the child's progress following intervention and also helps in setting intervention goals.

In comparison to ICF-CY questionnaire for Autism developed by Gan et al. (2013), it does not focus more on identifying the strengths of children with ASD since it assesses only their disabilities/weaknesses. Among the children with the same diagnosis and severity level, it does not profile the uniqueness in their functional abilities. Lastly, the level of difficulty was not assessed for all the items of each domain and importance was not given for identifying the facilitators and barriers for the child's functioning.

The efficacy of the integrated use of functional perspectives with diagnostic outcomes

Castro et al. (2013) study compared the content of International Classification of Functioning, Disability and Health - child and youth version with other various ASD traditional instruments namely ADI-R, ADOS and CARS. The authors had linked the items of each of the diagnostic tools namely Autism Diagnostic Inventory –Revised (ADI-R), Autism Diagnostic Observation Schedule (ADOS) and Childhood Autism Rating Scale (CARS) with International Classification of Functioning Health and Disability for Children and Youth (ICF-CY) functional framework and found a strong agreement between the mentioned assessment tools and International Classification of Functioning Health and Disability for Children and Youth (ICF-CY).

Based on the linking process of Autism Diagnostic Inventory –Revised (ADI-R) with International Classification of Functioning Health and Disability for Children and Youth

(ICF-CY), the results revealed that the major meaningful concepts identified in Autism Diagnostic Inventory –Revised (ADI-R)'s items were Body Functions (55.9%) and Activities/ Participation (51.6%). The attitude of the parent/caregiver towards the child's functional performance was considered as the only dimension of the Environmental Factor to be linked with the contents of Autism Diagnostic Inventory –Revised (ADI-R).

The linking process of Autism Diagnostic Observation Schedule (ADOS) with International Classification of Functioning Health and Disability for Children and Youth (ICF-CY) reveals similar results to that of the linking process between Autism Diagnostic Inventory –Revised (ADI-R) and International Classification of Functioning Health and Disability for Children and Youth (ICF-CY). The major meaningful concepts identified in Autism Diagnostic Observation Schedule (ADOS) were Body Functions (47.7%) and subsequent to it was Activity/Participation (43.2%). The only difference to the previous mentioned results (ADI-R with ICF-CY linkage) is that Environmental Factors were not assessed using Autism Diagnostic Observation Schedule (ADOS).

According to the results of the linking process of Childhood Autism Rating scale (CARS) with International Classification of Functioning Health and Disability for Children and Youth (ICF-CY), the commonly identified meaningful concepts in Childhood Autism Rating scale (CARS) was Body Functions (96.1%) followed by Activities/ Participation (43.1%). The drawback to this measurement tool namely Childhood Autism Rating scale (CARS) was, Environmental Factors were not identified in any of the identified meaningful concepts.

Castro et al. (2013) had concluded the study by stating that the linkage between these mentioned ASD assessment tools (ADI-R, ADOS and CARS) and International Classification of Functioning Health and Disability for Children and Youth (ICF-CY) assists the speech language pathologists in

1) Profiling the assessment and intervention outcomes of specific functional aspects using a universal language

2) Combining diagnostic and functional data

These diagnostic tools were found to provide limited information on specific functional aspects beyond the Autism diagnostic criteria. Integrating functional perspective with diagnostic outcomes proved to be helpful in highlighting the functional differences among children who were diagnosed as Autism spectrum Disorders and also individualizing the assessment-intervention process. de Schipper et al. (2015) had reported that by integrating DSM and ICF-CY, the consequence of the triad symptoms on functioning of pre-school children with Autism can be understood with respect to ICF-CY framework.

CHAPTER II

Methodology

Participants

20 pre-school children who had been diagnosed with Autism were considered for the study. The sample comprised of 17 males and 3 females. Among 20 pre-school children with autism, four of them were diagnosed as mild autism, 14 of them were diagnosed as moderate autism and 2 of them were diagnosed as severe autism.

The participants of the present study had met the following inclusion criteria

The twenty pre-school children who were diagnosed with Autism were in the age range of 3-6 years. Their diagnosis was made by using the standardized test named Differential diagnosis checklist for Autism Spectrum Disorders (DDC-ASD) (Chengappa et al. 2007). They were either enrolled in mainstream or in special school or unschooled.

Exclusion criteria set for the present study

Pre-school children with comorbid disorders linked with Autism and those who were diagnosed with Rett's disorder, Childhood disintegrated disorder, PDD-NOS and Asperger's syndrome were excluded from the study.

The study was carried out in two phases

Phase 1 - An ICF-CY based assessment tool for children with autism was adapted and modified to administer it on Indian Pre-school Children with Autism.

Phase 2 – The so developed ICF-CY based parent report functional assessment questionnaire for Autism was administered to English speaking caregivers of these 20 pre-school children with Autism in order to account information on their child's functional competencies in four domains namely Body Functions, Activities, Participation and Environmental Factors. For caregivers who were unable to understand English, an interpreter of their language was used.

PHASE 1 was carried out in following steps

1) Framing Neutral Statements for the items of four domains to modify and develop the questionnaire

2) Validation of the Questionnaire

3) Framing the ICF-CY Qualifier scale for each of the four domains

4) Pilot Study was done to assess the feasibility of utilizing the questionnaire in clinical practice

5) Administration of modified ICF-CY based Functional assessment questionnaire for measuring Inter-Rater Reliability

Each step will be discussed in detail below

STEP1 - Framing Neutral Statements for the items of four domains to modify and develop the questionnaire

The modified ICF-CY based Parent Report Functional assessment tool for Autism consisted of four domains namely Body functions, Activities, Participation and

Environmental factors. Out of 118 items, 114 items belonged to these four domains were adapted from Taiwanese based ICF-CY assessment tool for Autism because of their appropriateness (Gan et al. 2013).

Body functions domain

This domain comprised of three sub-domains such as Mental Functions, Sensory Functions and Pain and Voice and Speech Functions. Overall, twenty six items were adapted from the body functions domain of the original ICF-CY based parent report questionnaire for Autism (Gan et. 2013).

Table 3.1

A list of adapted items belonging to the three sub-domains of Body Functions domain.

Mental Functions sub-domain (13 items)	**Sensory Functions and Pain sub-domain (9 items)**	**Voice and Speech Functions sub-domain (4 items)**
b1250 Adaptability	b1560 Auditory perception	b320 Articulation functions
b1252 Activity	b1561 Visual perception	b3300 Fluency of speech
b1254 Persistence	b1565 Visuospatial perception	b3302 Speed of speech
b1342 Maintenance of sleep	b2801 Sensation of body pain	b3303 Melody of speech
b1400 Sustaining attention	b250 Taste function	
b1401 Shifting attention	b255 Smell function	
b1402 Divided attention	b265 Touch function	
b1403 Sharing attention	b2703 Sensitivity to a noxious stimulus	
b1440 Short term memory	b279 Eye hand coordination	
b1441 Long term memory		
b1520 Appropriateness of emotion		
b1521 Regulation and control of emotion		
b7653 Inhibitory control of stereotypies and motor perseveration		

Activities domain

The activities domain consisted of five sub-domains namely Learning and Applying Knowledge, General Task and Demands, Communicating- Receiving, Mobility and Self-

Care. Overall, Forty items were adapted from the activities domain of the original ICF-CY based parent report questionnaire for Autism (Gan et al. 2013).

The Learning and Applying knowledge sub-domain comprised of 17 items such as

d130 Immediate imitation of an action or behavior, d1311 Learning through actions relating two or more objects, toys or materials, d1314 Learning through pretend play, d1313.Learning through symbolic play, d1330 Acquiring single words, d1331 Combining words into phrases, d1332 Acquiring syntax, d135 Rehearsing, d1370 Acquiring basic concepts, d1371 Acquiring complex concepts, d1400 Acquiring skills to recognize alphabets and words, d1401 Acquiring skills to read written words, d1500 Acquiring skills to recognize numbers, d1501 Acquiring skills of numeric such as counting and ordering, d1600 Attending to the human touch, face and voice, d1601 Attending to changes in the environment and d161 Intentionally directing attention to a specific activity for an appropriate length of time

General Tasks and Demands sub-domain comprised of three items such as

d2100 Undertaking a simple task that is preparing, initiating and arranging the time and space required for a simple task

d2300 Following routines

d2304 Acceptance of novelty with positive actions

Communicating – receiving sub-domain comprised of 6 items namely

d3101 Comprehending the simple spoken messages

d3102 Comprehending the complex spoken language

d3150 Communicating with - receiving - body gestures

d3350 Producing body language

d330 Producing words, phrases and longer passages in spoken messages

d331 Acquiring information that is obtaining facts about persons, things and events (such as asking why, what)

Mobility sub-domain comprised of 3 items such as

d440 Fine coordinated hand use

d4454 Throwing ball

d4455 Catching ball

Self-care sub-domain comprised of 11 items such as

d5100 Washing a specific body part when asked to

d5101 Washing whole body

d5201 Brush teeth

d53000 Indicating need for urination

d53001 Carrying out urination appropriately

d53010 Indicating need for defecation

d53011 Carrying out defecation appropriately

d5400 Putting on clothes

d5402 Putting on footwear

d550 Eating in culturally acceptable ways

d571 Avoiding potentially dangerous situations and harm to self

Participation domain

This domain included three sub-domains such as Communicating-Conversation, Interpersonal Interactions and Relationships and Domestic Life/ Major Life Areas. Thirty six items from participation domain were adapted from the original ICF-CY based parent report questionnaire for children with Autism. In the Taiwanese based ICF-CY assessment tool for Autism (Gan et al. 2013), the level of support and duration of assistance for each activity mentioned in this domain were considered as separate items whereas in the modified ICF-CY based parent report questionnaire for Autism, it was considered together. And so, the participation domain comprised of 18 items.

Table 3.2

A list of adapted items belonging to three sub-domains of Participation domain.

Communicating-Conversation subdomain (3 items)	Interpersonal Interactions and Relationships subdomain (7 items)	Domestic Life/Major Life Areas (8 items)
d3500 Starting a conversation	d7101 Appreciation in relationships	d6302 Helping in serving meals
d3501 Sustaining a conversation	d7109 Taking turns in social interactions	d6406 Helping to do housework
d3600 Using telephone	d7105 Physical contact in relationships	d810 Learning at home
	d7203 Interacting according to social rules	d8151 Engaging in structured activities in group settings
	d7601 Child-parent relationships	d8800 Solitary play
	d7602 Sibling relationships	d8801 Onlooker play
	d7603 Extended family relationships	d8802 Parallel play
		d8803 Shared cooperative play

Environmental Factors domain

The last domain which is the environmental factor comprised of three sub-domains such as products and technology, support and relationships and attitudes. Twelve items were adapted from the environmental factors domain of the original questionnaire.

Table 3.3

A list of adapted items belonging to three sub-domains of Environmental Factors domain.

Products And Technology sub-domain (2 items)	Support And Relationships subdomain (4 items)	Attitudes sub-domain (6 items)
e11520 General products and technology for play e1300 General products and technology for education	e310 Parents support e315 Extended family support e320 Peers and neighbours' support e355 Health professionals support	e410 Parents' attitudes e415 Attitudes of extended family members e425 Peers' attitudes e455 Teachers' attitudes e450 Health professionals' attitudes e460 Societal attitudes

In an effort to adapt the tool to our context (South Indian Mysore, AIISH context), several modifications which are mentioned below were undertaken

1) The neutral statements were framed for the 26 adapted items of body functions domain, 40 adapted items of activities domain and 18 adapted items of participation domain.

2) In the last domain that is the environmental factors domain, the neutral statements were framed for the two adapted items of products and technology sub-domain and four adapted items of support and relationships sub-domain.

3) In addition to the above mentioned modification, six neutral statements (where 3 statements conveyed positive attitudes and the other three conveyed negative attitudes) were framed for each of the adapted six items (such as parents' attitudes, individual

attitudes of extended family members, peers' attitudes, teachers' attitudes, health professionals' attitudes and societal attitudes) of attitude sub-domain.

4) The activities which were relevant to 3 to 6 year old children with autism were mentioned in the illustrations for each statement in order to ease the parents in understanding the questions asked.

On the whole, **the modified ICF-CY based Parent Report Functional assessment tool for Autism consisted of one hundred and twenty six neutral statements**. These framed neutral statements were sensitive to assess impairments of body functions, activity limitation, and participation restriction and also to identify the environmental barriers and facilitators.

STEP 2- Validation of the Questionnaire

Five SLP post-graduate students were asked to rate each framed neutral statement for the process of validation. Judges were asked to rate the framed neutral statements based on concept and understandability of each statement. They were asked to respond by marking each neutral statement as 'Understandable' or 'Fairly understandable' or 'Not understandable'. The statements with 75% agreement between the five judges were included in the inventory. The statements for the items belonging to attitudes sub-domain (e410, e415, e425, e455, e450 and e460), b1401 item from mental functions sub-domain and d1371 item form learning and applying knowledge sub-domain were rated as fairly understandable by three out of five judges and these statements were modified as per the suggestions given.

STEP 3- Framing the ICF-CY Qualifier scale for each of the four domains

The ICF-CY qualifier scoring scale was framed for four domains namely Body functions, Activities, Participation and Environmental factors. This scoring scale for each domain was framed in relevance to the ICF-CY framework (World Health Organization 2007). Modifications were made to the scoring scale of Body functions and Environmental factors. The scoring as given in ICF-CY is listed below

Rating for Body Functions domain

- **0-** No difficulty (None, Absent, Negligible)
- **1-** Mild difficulty (Slight, Low)
- **2-** Moderate difficulty (Medium, Fair)
- **3-** Severe difficulty (High, Extreme)
- **4-** Profound difficulty (total)

The scoring scale for impairment in Body function domain indicates the severity of the problem. If the level of problem is more, then the impairment of body functions is more severe.

Rating for Activities domain

- **0-** No difficulty(completely independent)
- **1-** Mild difficulty (Slightly independent)
- **2-** Moderate difficulty (Fairly independent)
- **3-** Severe difficulty (Extremely dependent)
- **4-** Profound difficulty (completely dependent)

The Scoring scale for Activities limitation indicates the difficulty level of the child in executing activities independently. The Low level of independency in performing a task indicates that the activities limitation is more severe.

Rating for Participation

- **0-** No difficulty (completely independent)
- **1-** Mild difficulty (Slightly independent)
- **2-** Moderate difficulty (Fairly independent)
- **3-** Severe difficulty (Extremely dependent)
- **4-** Profound difficulty (completely dependent)

The scoring scale for Participation domain indicates the extent of support and duration of assistance required for the child to participate or execute or perform the given task in real life situations. The Low level of independency in performing a task in real life situations indicates that participation restriction is more severe.

Rating for Environmental factors

- **0-** No Barrier
- **1-** Mild Barrier
- **2-** Moderate Barrier
- **3-** Severe Barrier
- **4-** profound barrier

Scoring for Environmental factor will indicate whether the statements focusing on attitudes, accessibility of the availing services and support act as a barrier or a facilitator

for the child's participation in relevant life situations. The environmental factor could be a barrier either because of negative attitudes towards children with autism or unavailability of a required service/assistance. A higher barrier score indicates that the environmental factor acts as a great hindrance for the child's participation i.e. it completely limits the child's functioning.

STEP 4 - Pilot Study

In order to check for the feasibility of utilizing the questionnaire in clinical practice, the modified questionnaire was administered by five master's degree holders in Speech Language Pathology on five children with autism. The raters were oriented on the use of the ICF-CY based parent report questionnaire for pre-school children with autism that is they were given instructions on the ways to assess the items from each domain and also on using the scoring scale for each domain. After administering the questionnaire, the raters reported that they did not find it difficult to assess pre-school children with autism using the ICF-CY based parent report questionnaire but they did give suggestions. Modification such as rewriting the negative statements belonging to support and relationships sub-domain of environmental factor domain as neutral statements were made as per the suggestions given.

STEP 5 - Administration of modified ICF-CY based Functional assessment questionnaire for measuring Inter-Rater Reliability

The modified/ adapted questionnaire was administered by two master's degree holders in Speech Language Pathology on one half of the sample within two weeks (1 week for each) and the Inter-rater reliability for the domain average scores were assessed. The

other rater was informed about the guidelines to administer the ICF-CY based questionnaire to pre-school children with autism (including the scoring guidelines).

PHASE2

The modified ICF-CY based questionnaire for autism was administered to 20 Indian pre-school children with autism (3 to 6 years age group) for the purpose of assessing their functional performance in three domains namely body functions, activities and participation and also for identifying the facilitators and barriers for the child's functioning.

The Consent for participation was obtained from all the 20 caregivers of children with autism using AIISH Ethical Committee guidelines (AEC).

Statistical Analysis

The statistical analysis of scores was done using SPSS software (21 version)

CHAPTER IV

RESULTS

The primary aim of the study was to modify the ICF-CY based parent report questionnaire for Children with Autism developed by Gan et al. (2013) and implement the modified version of ICF-CY based parent report questionnaire in Indian context for pre-school children with Autism.

The results of the study will be presented under the following sections

1) Determining the reliability of the modified version of ICF-CY based parent report functional assessment questionnaire for pre-school children with autism

2) The functional performance level of Pre-school children with autism in 4 domains namely Body Functions, Activities, Participation and Environmental Factors

3) Determining the relation of difficulties on the activities and participation level faced by pre-school children with autism with problems either in body functions or due to environmental factors

Determining the reliability of the modified version of ICF-CY based parent report functional assessment questionnaire for pre-school children with Autism

Inter-rater reliability and internal consistency were done to assess the reliability of the modified ICF-CY based parent report questionnaire for pre-school children with Autism.

Results of Inter-rater reliability

The two raters had administered the modified ICF-CY based parent report questionnaire on 10 pre-school children who were diagnosed with autism. For each of the four domains, the consensus between the two judges' average domain scores was analyzed using a statistical measure named Cronbach's Alpha.

Table 4.1

Cronbach's Alpha values for all the domains' (Body functions, Activities, Participation and Environmental Factors) average scores obtained by two raters.

Domain	Cronbach's Alpha (α)	N of items
Body Functions	0.994	2
Activities	0.998	2
Participation	0.995	2
Environmental Factors	0.981	2

The level of agreement between the two raters on the usage of the Body Functions domain's rating scale (to rate the severity of the participants 'problem), Activities domain's rating scale (to rate the difficulties of the participants in executing activities independently), Participation domain's rating scale (to rate the extent of support and duration of assistance required for the participants to execute the given activity in real life situations) and the Environmental Factors domain's rating scale (to rate the statements focusing on attitudes, accessibility of the availing services and support as a barrier or facilitator for the child's participation in relevant life situations) were found to be

excellent and this elucidates that both the raters share a common interpretation of all the four domains' rating scales.

Internal Consistency

Cronbach's alpha reliability coefficient was measured to check for the internal consistency of all the four domains of this modified version of Parent based ICF-CY questionnaire for pre-school children with autism. The item analysis was done for all the statements of each domain.

Table 4.2

Cronbach's alpha reliability coefficients for the four domains.

Domain	Cronbach's Alpha (α)	N of items
Body Functions	0.917	26
Activities	0.939	40
Participation	0.841	16
Environmental Factors	0.788	16

The Overall Internal Consistency for the Body Functions domain (α= 0.917) and Activities domain (α= 0.939) was found to be excellent. For the Participation domain, the overall internal consistency was found to be good (α= 0.841) whereas for the Environmental Factors domain, it was found to be acceptable (α= 0.788) (Cronbach's $\alpha >$ 0.70 is considered as acceptable). The item wise internal consistency was also measured for all the four domains and its results revealed that, if each statement of the body functions domain, activities domain and participation domain was deleted, the overall

Internal Consistency of these three domains did not improve since the Cronbach's alpha if item deleted values were found to be around the overall Alpha of each of these domains. For the environmental factors domain, it was found that if e1300 and e410D items of the Environmental Factors domain were deleted, the overall internal consistency of the Environmental Factors domain would increase to 0.8.

Note: Majority of the parents of pre-school children with autism reported as not applicable to these statements d7602, d 8151 and so internal consistency was not checked for these two statements which belonged to participation domain. They had also reported as not applicable to these statements such as e410A, e410B, e410C, e410E, e410F, e415A, e415B, e415C, e425A, e425B, e425C, e425D, e425E, e425F, e455A, e455B, e455C, e455D, e455E, e455F, e450A, e450B, e450C, e460A, e460B, and e460C and so internal consistency was not checked for these mentioned statements which belonged to environmental factors domain.

The functional performance level of Pre-school children with autism in 4 domains namely Body Functions, Activities, Participation and Environmental Factors

The total raw scores obtained on all the four domains (body functions, activities, participation and environmental factors) were converted to percent scores. Then mean and median percent scores and standard deviation scores were calculated in order to investigate which domain were scored as having the highest and least level of disability for the participants.

Table 4.3

Percent mean and median and Standard Deviation scores of four domains.

	Body functions percentage	**Activities percentage**	**Participation percentage**	**Environmental factors percentage**
N	20	20	20	20
Percent Mean score	46.45	54.15	62.70	14.95
SD	17.721	18.345	13.083	11.237
Percent Median score	47.50	59.50	65	11.50

The results revealed that highest level of disability was seen in the Participation domain followed by Activities domain whereas the lower level of impairment was seen in the Body Functions domain. The Environmental Factors domain were found to have the least barrier scores which indicates that it limits these children's functioning to a least extent i.e. these participants had least level of disability because the hindrance was small.

Among the sub-domains of each of the four domains, their functional performance level was assessed

The total raw scores obtained on the subdomains of each domain were converted to percent scores. Then mean and median percent scores and standard deviation scores were calculated for the subdomains of each domain. With regard to the percentage mean and median scores and standard deviation scores obtained for the sub-domains of body functions, the subdomains which received the highest and lowest levels of impairment would be found out. For activities and participation domains, the sub-domains in which these participants perform with highest and least level of difficulties would be

documented whereas for environmental factors domain, the sub-domains which had the highest and least barrier scores would be found out.

Performance level of Pre-school children with Autism in Body Functions domain

Table 4.4

Percent mean and median and Standard Deviation scores of three sub-domains of body functions domain.

	Mental functions percentage	**Sensory Functions and Pain percentage**	**Voice and Speech functions percentage**
N	20	20	20
Percent Mean score	46.80	36.65	67.05
SD	20.222	16.060	28.589
Percent Median Score	47	42	78

The results revealed that highest level of impairment was seen in the Voice and Speech Functions followed by Mental Functions whereas the least level of impairment was seen in the Sensory Functions and pain sub-domain.

Performance of Pre-school children with Autism in Activities domain

Table 4.5

Percent mean and median and Standard Deviation scores of five sub-domains of activities domain.

	Learning and Applying Knowledge percentage	**General Tasks and Demands Percentage**	**Communicating –Receiving percentage**	**Mobility percentage**	**Self-Care percentage**
N	20	20	20	20	20
Percent Mean score	65.25	45.35	61.30	23.30	43.55
SD	22.062	20.724	15.284	29.093	23.867
Percent Median score	73	46	58	12.50	44

The results of the percent mean and median for the five subdomains (Learning and Applying Knowledge, General Tasks and Demands, Communicating – Receiving, Mobility and Self-care) of Activities domain revealed that the least level of difficulties was seen in the mobility sub-domain and the highest level of difficulties was seen in Learning and Applying Knowledge followed by Communicating-Receiving.

Performance of Pre-school children with Autism in Participation domain

Table 4.6

Percent mean and median and Standard Deviation scores of three sub-domains of participation domain.

	Communicating– Conversation percentage	**Interpersonal interactions and Relationships percentage**	**Domestic life/Major Areas percentage**
N	20	20	20
Percent Mean score	87.10	58.05	56.60
SD	18.052	14.468	13.112
Percent Median score	100	61	56

The results revealed that highest level of difficulties was seen in the Communicating – Conversation followed by Interpersonal interactions and Relationships whereas the least difficulty was seen in the Domestic life/Major Areas.

Performance of Pre-school children with Autism in Environmental Factors domain

Table 4.7

Percent mean and median and Standard Deviation scores of three sub- domains of environmental factors domain.

	Products and Technology percentage	**Support and Relationships percentage**	**Attitudes percentage**
N	20	20	20
Percent Mean score	17.65	20.20	14.10
SD	22.894	17.111	12.485
Percent Median score	.00	16	10.50

The results of the percent mean and median scores for the three subdomains (Products and Technology, Support and Relationships and Attitudes) of Environmental Factors domain revealed that the Support and Relationships sub-domain received the highest barrier score followed by the Products and Technology whereas the lowest barrier score was found in the attitudes sub-domain.

Item analysis was carried out for all the four domains namely Body Functions, Activities, Participation and Environmental Factors

For each of the items in each domain, two frequency tables were computed; one with reference to the scoring 0 and the other with reference to the summation of percentage values of scorings 3 and 4; where 0 indicates no difficulty, 3 indicate severe difficulty and 4 indicates profound difficulty for body functions, activities and participation domains. But for environmental factors domain, 0 indicates no barrier, 3 indicates severe barrier and 4 indicates profound barrier.

Statements scored as 0 which had frequency above 60% were interpreted as these children with autism do not have difficulty in performing those functional activities with respect to body functions domain. With respect to Activities domain, it was interpreted as these children with autism could execute those activities independently. For participation domain, it was interpreted as they could execute those activities independently in real life situations. For environmental factors domain, Statements focusing on products and technology, support and relationships and positive attitudes which were scored as 0 having frequency above 60% were interpreted as those statements act as a facilitator for the subjects' functional performances.

On summating the percentage values for scorings 3 and 4 for all the statements, statements which had frequency above 60 % were interpreted as these children with autism had severe-profound problem in performing those functional activities with respect to body functions domain. With respect to Activities domain, it was interpreted as they were severe – profound difficulty in executing the tasks. For Participation domain, it was interpreted as they were severe – profoundly dependent on their care-givers for executing the tasks in real life situations. Lastly, with respect to environmental factors domain, it was interpreted as those statements focusing on products and technology, support and relationships and positive and negative attitudes were considered as severe-profound barriers for the subjects' functional performances. The frequency distribution for all the statements in each domain has been depicted in graphical representations.

Majority of the statements belonging to Body Functions domain which were rated as having no difficulty in performing those functional activities will be discussed below

Statements scored as 0 which had frequency above 60% were b1250, b1342, b1560, b2801, b250, b2703 and b279. Under **Mental Functions sub-domain**, 90 % of the children with autism had no problem in sleeping without disturbance and 60% of them had no problem in reacting to new objects or experiences in an interested way. Under **Sensory Functions and Pain sub-domain**, 90% of them had no problem in recognizing taste differences, 80% of them had no problem in sensing pain when felt in specific part of the body, 75% of them had no problem in discriminating loud vs soft sounds or pleasant vs unpleasant sounds, 65% of them had no problem in sensing painful or uncomfortable sensations and lastly, 60% of them had no problem in eye hand

coordination. Under **Voice and Speech Functions**, none of the statements scored as 0 had frequency above 60%.

Table 4.8

Frequency of statements belonging to Body Functions domain which were rated as having no difficulty in performing those functional activities has been arranged in descending order.

Statements	**Frequency**
b1342: Ability to sleep for 8-9 hours without disturbance	90%
b250: Ability to recognize the taste differences	90%
b2801: Ability to sense pain or discomfort felt in a specific part of the body	80%
b1560: Ability to discriminate loud vs soft sounds and pleasant vs unpleasant sound	75%
b2703: Ability to sense painful or uncomfortable sensations	65%
b279: Ability to handle or manipulate objects	60%
b1250: Ability to act or react in an interested way to new objects or experiences	60%

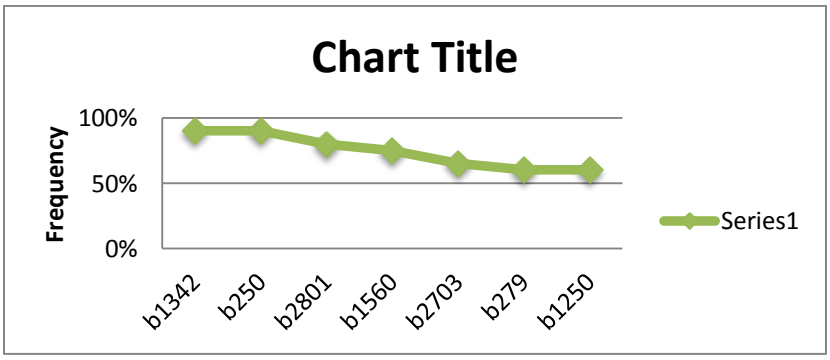

Figure 4.1. Frequency of statements belonging to Body Functions domain which were rated as having no difficulty in performing those functional activities

Majority of the statements belonging to Body Functions domain which were rated as having severe - profound problem in performing those functional activities will be discussed below

On summating the percentage values of scorings 3 and 4 for all the statements in body functions domain, the statements which had frequency above 60% were b3300, b3302, b1254, b1400, b1401, b1402, b1561, b255 and b265. Under **Mental Functions sub-domain**, 85% of them had severe-profound problem in divided attention, 70% of them had severe- profound problem in sustaining attention in an activity, 65% of them had severe- profound problem in completing a task with sustained effort and 60% of them had severe- profound problem in shifting attention. Under **Sensory Functions and Pain sub-domain**, 70% of them had severe to profound problem in grouping objects based on size, shape and color and also in sensing and recognizing the difference based on the objects' texture and 60% of them had severe- profound problem in sensing pleasant and unpleasant odor. Under **Voice and Speech Functions sub-domain**, 80% of them had severe- profound problem in speaking fluently without interruptions and also in speaking at a normal pace.

Table 4.9

Frequency of statements belonging to Body Functions domain which were rated as having severe-profound difficulty in performing those functional activities has been arranged in descending order.

Statements	Frequency
b1402: Ability to respond to more than one task simultaneously	85%
b3300: Ability to speak fluently without any interruptions	80%
b3302: Ability to speak at a normal pace	80%
b1400: Ability to sustain attention in an activity	70%
b1561: Ability to group the objects based on shape, size and colour	70%
b265: Ability to sense and recognize the difference based on the objects' texture	70%
b1254: Ability to complete a task with sustained effort	65%
b1401: Ability to refocus attention from an object/activity to another object/activity	60%
b255: Ability to sense pleasant and unpleasant odour	60%

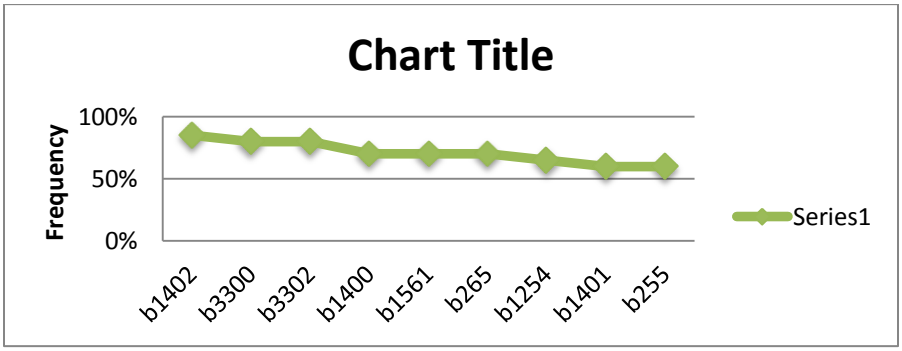

Figure 4.2. Frequency of statements belonging to Body Functions domain which were rated as having severe-profound difficulty in performing those functional activities

Majority of the statements belonging to Activities domain which were rated as having no difficulty in performing those functional activities will be discussed below

Statements scored as 0 which had frequency above 60% were d1601, d2304, d3101, d4454, d4455, d53000, d53010 and d571. Under **Learning and Applying Knowledge**

sub-domain, 60% of them were able to recognize the modifications made to one's own environment independently. Under **General Tasks and Demands sub-domain**, 65% of them were able to respond appropriately to changes in usual sequence of activities/daily routines. Under **Communicating-Receiving sub-domain**, 60% of them were completely independent enough to respond to requests or commands through actions or with words. Under **mobility sub-domain**, 75% of them were able to throw ball or tossing coin independently and 70% of them had no difficulty in catching objects independently. Under **self-care sub-domain**, 80% of them were able to indicate need for urination and also defecation independently and 60% of them were completely independent enough to protect themselves from danger/harm/injury.

Table 4.10

Frequency of statements belonging to Activities domain which were rated as having no difficulty in performing those functional activities has been arranged in descending order.

Statements	**Frequency**
d53000: Ability to indicate need for urination	80%
d53010: Ability to indicate need for defecation	80%
d4454: Ability to throw ball or toss coin	75%
d4455: Ability to catch objects	70%
d2304: Ability to respond appropriately to changes in usual sequence of activities/daily routines	65%
d1601: Ability to recognize the modifications made to one's own environment	60%
d3101: Ability to respond to requests or commands through actions or with words	60%
d571: Ability to protect oneself form danger/harm/injury	60%

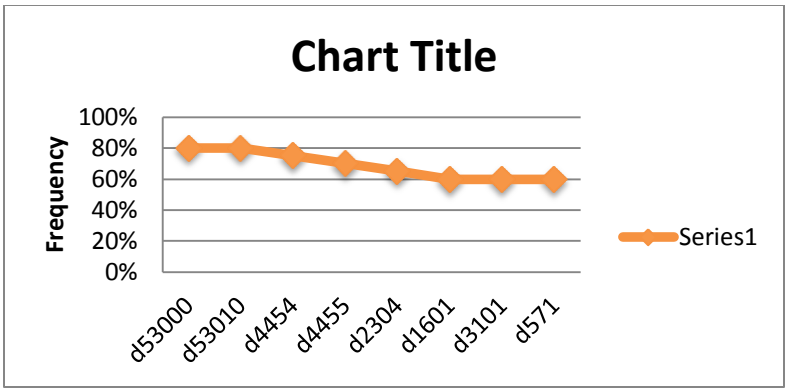

Figure 4.3. Frequency of statements belonging to Activities domain which were rated as having no difficulty in performing those functional activities

Majority of the statements belonging to Activities domain which were rated as having severe- profound difficulty in performing those functional activities will be discussed below

On summating the percentage values of scorings 3 and 4 for all the statements in activities domain, the statements which had frequency above 60% were d1313, d1311, d1314, d1332, d1370, d1330, d1371, d1331, d1401, d135, d1501, d1400, d1500, d2100, d161, d3102, d330, d331, d5400 and d5402.

Under **Learning and Applying Knowledge sub-domain**, 80% of them were reported to have severe-profound difficulty in counting and arranging numbers in ascending and descending order, 75% of them had severe-profound difficulty in using real objects/props to enact a particular event and also in narrating events /requesting things verbally in a correct sentence order, 70% of them were severe-profound difficulty in describing the object based on size, shape, length, using quantity markers (more/less) and/ recognizing the opposites, generating a list of items for a lexical or grouping the objects with respect

to its identity or its role for an activity, using semantic relations (two word combinations), reading aloud and recognizing the letters, symbols and words and also for sustaining one's focus on a specific task or event, 65% of them were reported to have severe- profound difficulty in learning through actions by associating two or more objects which are used to perform a particular event, expressing meaningful words and also in recognizing numbers and lastly, 60% of them had severe- profound difficulty in using inanimate objects to enact a particular event and also in practising recitals. Under **General Tasks and Demands sub-domain**, 85% of them had severe-profound difficulty in planning, initiating and making temporal and spatial arrangements in order to complete a simple task.

Under **Communicating –Receiving sub-domain**, 95% of them were severe-profoundly dependent on care-givers for narrating events or stories or expressing one's needs, 90% of them had severe- profound difficulty in responding to questions or instructions through actions or with words and 85% of them had severe- profound difficulty in generating WH questions. Under **Self-Care sub-domain**, 75% of them were severe-profoundly dependent on care-givers for wearing socks, tying shoe lace and putting sandal buckles and 65% of them had severe- profound difficulty in wearing clothes.

Table 4.11

Frequency of statements belonging to Activities domain which were rated as having severe- profound difficulty in performing those functional activities independently has been arranged in descending order.

Statements	**Frequency**
d330: Ability to describe, narrate events or stories or express one's own needs	95%
d3102: Ability to respond to questions or instructions through actions or with words	90%
d331: Ability to generate Wh questions to seek specific information about person, things and events	85%
d2100: Ability to plan, initiate and make temporal and spatial arrangements in order to complete a simple task	85%
d1501: Ability to count numbers and arrange numbers in ascending or descending order	80%
d1313: Ability to use real objects/props to enact a particular event	75%
d5402: Ability to wear socks, tie shoelace and put sandal buckles	75%
d1332: Ability to describe or narrate events or request things verbally in a correct sentence order	75%
d1370: Ability to describe the object based on size, shape, length, use quantity markers (more/less) and recognize the opposites	70%
d1371: Ability to generate a list of items for a lexical or group the objects with respect to its identity or its role for an activity	70%
d1331: Ability to use semantic relations (two word combinations)	70%
d1400: Ability to recognize alphabet letters, symbols and words	70%
d1401: Ability to read aloud the letters, symbols and words	70%
d161: Ability to sustain one's focus on a specific task or event	70%
d5400: Ability to wear clothes, gloves, put the shirt buttons and zips the pant	65%
d1311: Ability to learn through actions by associating two or more objects which are used to perform a particular event	65%
d1500: Ability to recognize numbers	65%
d1314: Ability to use inanimate objects to enact a particular event	60%
d135:Ability to practise recitals	60%

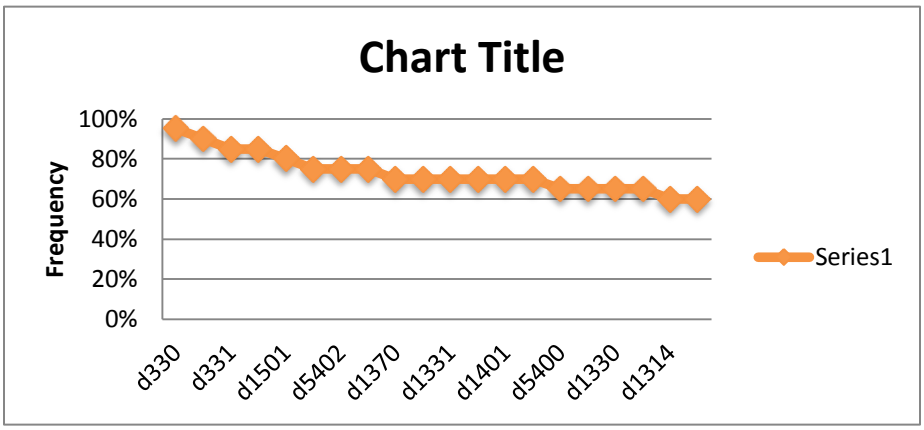

Figure 4.4. Frequency of statements belonging to Activities domain which were rated as having severe- profound difficulty in performing those functional activities

The only statement belonging to Participation domain which was rated as having no difficulty in performing that functional activity will be mentioned below

The only statement scored as 0 which had frequency above 60% was d8800. Under **Domestic and Major life areas sub-domain**, 80% of them were completely independent enough to play alone with toys.

Majority of the statements belonging to Participation domain which were rated as having severe- profound difficulty in performing those functional activities will be discussed below

On summating the percentage values of scorings 3 and 4 for all the statements in participation domain, the statements which had frequency above 60% were d3501, d3600, d7203, d6406, d3500, d7101, d7109, d7601, d6302, d810, d8151 and d8803.

Under **Communicating-conversation sub-domain**, 95% of them were severe-profoundly dependent on care-givers to sustain conversation, 80% of them had severe-

profound difficulty in making a call independently and lastly, 70% of them were severe-profoundly dependent on care-givers for introducing oneself or a topic or asking questions or greeting people voluntarily. Under **Interpersonal interactions and Relationships sub-domain**, 95% of them were reported to have severe- profound difficulty in interacting with others independently and varying the speaking style in accordance to the recipient's role, 85% of them were severe-profoundly dependent on care-givers for showing or responding a sense of satisfaction and gratitude in a culturally acceptable manner, 80% of them had severe- profound difficulty in taking turns independently in verbal group activities and 70 % of them had severe- profound difficulty in being obedient to parents and taking care of them in times of need independently.

Under **Domestic life/Major life areas sub-domain**, 85% of them were severe-profoundly dependent on caregivers for playing social games with others with a shared goal and also for rendering a helping hand in planning, organizing and managing household work, 70% of them had severe- profound difficulty in rendering a helping hand in serving meals, 60% of them had severe-profound difficulty in acquiring academic and non-academic skills from their family members and lastly, 60% of them were severe-profoundly dependent on care-givers for attending classes, interacting with peers and obeying the rules stated for students

Table 4.12

Frequency of statements belonging to participation domain which were rated as having severe-profound problem in performing those functional activities independently in real life situations has been arranged in descending order.

Statements	**Frequency**
d3501: Level of support and the duration of assistance required for the child to sustain conversation	95%
d7203: Level of support and duration of assistance needed for the chid to interact with others independently and vary the speaking style in accordance with the recipient's role in the society	95%
d7101: level of support and the duration of assistance needed for the child to show or respond with a sense of satisfaction and gratitude in a culturally acceptable manner	85%
d8803: Level of support and duration of assistance required for the child to play social games with others with a shared goal or purpose	85%
d6406: Level of support and duration of assistance required for the child to render a helping hand in planning, organizing and managing household work	85%
d3600: Level of support and the duration of assistance required for the child to make a call independently	80%
d7109: Level of support and the duration of assistance required for the child to take turns in group activities (V)	80%
d3500: Level of support and the duration of assistance required for the child to introduce oneself (V/NV) or a topic or ask questions or greet people voluntarily	70%
d6302: Level of support and duration of assistance required for the child to render a helping hand in serving meals	70%
d7601: Level of support and duration of assistance required for the child to be obedient to parents and take care of them in times of need	70%
d810: Level of support and duration of assistance required for the child to acquire academic skills and non- academic skills from family members or parents	60%
d8151: Level of support and duration of assistance required for the child to attend classes, interact with peers and obey the rules stated for students	60%

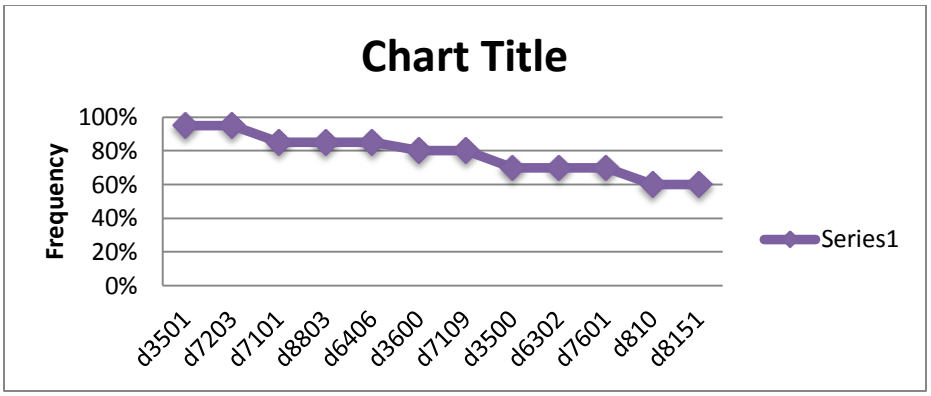

Figure 4.5. Frequency of statements belonging to participation domain which were rated as having severe-profound problem in performing those functional activities independently in real life situations

Majority of the statements which were rated as facilitators for the participants' functioning

Statements scored as 0 which had frequency above 60% were e11520, e1300, e310, e315, e355, e410D, e415D, e415E, e415F, e425B, e450D, e450E, e460D,e460E and e460F. **Under Products and Technology sub-domain**, playing with toys and puzzles were considered as a facilitator for 70% of the children with autism and Accessing books, educational toys and computer had facilitated 60% of them to acquire knowledge.

Under **Support and Relationships sub-domain**, support provided by the parents and health professionals had positively influenced 85% of the subjects' behavior whereas support provided by the participant's relatives had positively influenced only 60% of the subjects' behavior.

Under **Attitudes sub-domain**, parents being determined to work towards their children's welfare was considered as a facilitator for all the children with autism (100%), health professionals being service oriented and skilled enough to handle children with autism

had positively influenced 95% of the subjects' behavior, 80% of the parents of subjects reported that their children's achievements being praised by their relatives and including them in festival celebrations by the society had positively facilitated the children's behavior, 75% of the parents of children with autism reported that willingness of the extended family members to stimulate them to communicate had positively influenced the children's behavior, 65% of the parents of subjects reported that being informed by the subjects' relatives about any rehabilitation programs and social acceptance had facilitated their children's behavior and lastly, 60% of the parents reported that including their children among their children's peer groups in social gatherings and a comfortable communicating environment provided by the society had positively influenced their children's behavior.

Table 4.13
Frequency of statements belonging to Environmental Factors domain which were rated as facilitator has been arranged in descending order.

Statements	**Frequency**
e410D: Determined to work towards the welfare of the child	100%
e450C: Service oriented	95%
e450D: Skilled enough to handle children with autism	95%
e310: Assistance provided by the parents influences the child's behaviour	85%
e355: Support provided by health professionals influences the child's behaviour	85%
e460D: Positively engaging these children in festival celebrations in order to make these children to be aware of these celebrations	80%
e415E: Praising/motivating the child with autism for his/her achievements	80%
e415D: Willingness to stimulate the child with autism to speak	75%
e11520: Playing with toys and puzzles influences your child's behavior	70%
e415F: Informing the parents of children with autism about any rehabilitation programs for the welfare of the child	65%
e460F: Accepting children with autism as part of their society	65%
e315: Assistance provided by child's relatives influences the child's behaviour	60%
e425B: Including children with autism in social gatherings	60%
e460E: Providing a comfortable environment for the child to socialize with others	60%
e1300: Accessing books, educational toys and computer	60%

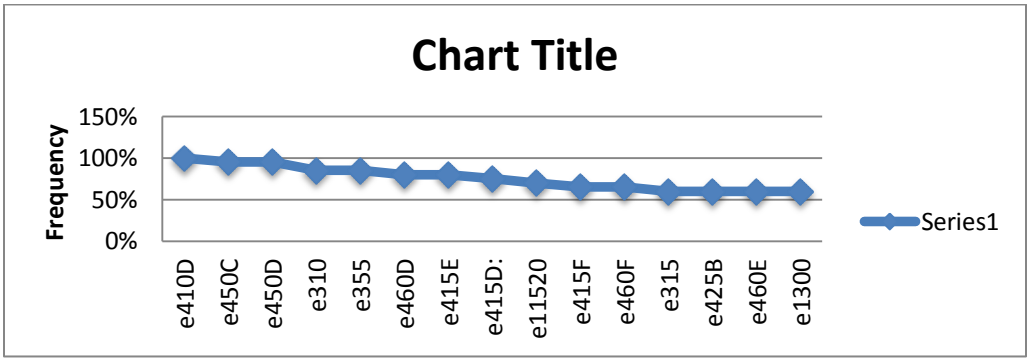

Figure 4.6. Frequency of statements belonging to Environmental Factors domain which were rated as facilitator

The summation of the percentage values of scorings 3 and 4 for all the statements in Environmental Factors domain revealed that none of the statements from products and Technology sub-domain, support and relationships sub-domain and attitudes sub-domain had frequency above 60%.

Determining the relation of difficulties on the activities and participation level faced by pre-school children with autism with problems either in body functions or due to environmental factors

The spearman correlation coefficient was used to measure the relationship between the domains such as Body Functions Vs Activities, Body Functions Vs Participation, Environmental Factors Vs activities, Environmental factors Vs Participation and Activities Vs Participation. Spearman correlation was used mainly for two reasons. Firstly, the variables in this study were not assumed to be normally distributed and secondly, the variables in this study were assumed to be ordinal.

The results of the correlation analysis revealed that a very strong positive correlation was found between Body Functions and Activities (ρ = .888) whereas a strong positive

correlation was found between Body Functions and Participation (ρ = .676). The Body Functions domain differed significantly from Activities domain (ρ = .000; where P < 0.01 (2 tailed)) and Participation domain (P = .001; where P < 0.01 (2 tailed)). Between Activities and Participation domains, a strong positive correlation (ρ = .753) was found and also a significant difference was found between Activities and Participation domains (P = .000; where P < 0.01 (2 tailed)). No significant difference was found between Environmental Factors and Activities domains (P = .384; where P >0.05 (2 tailed)) or Participation (P = .295; where P>0.05 (2 tailed)).

Thus, the strongest correlation was found between Body Functions and Activities domain followed by Activities Vs Participation and Body Functions Vs Participation. No significant difference between the domains such as Environmental Factors Vs Activities and Environmental Factors Vs Participation implies that there was no correlation between Environmental Factors and Activities or Participation. The correlation analysis results led to a conclusion that the difficulties on the activities and participation level faced by these 20 pre-school children with autism were influenced by problems in one's own Body Functions and not by environmental factors.

CHAPTER V

DISCUSSION

The **modified version of ICF-CY based functional assessment questionnaire for pre-school children with autism was found to be a reliable tool for assessing the functional abilities of pre-school children with autism in Indian context.** Because this questionnaire demonstrated excellent inter-rater reliability on the usage of four domains' (namely, Body Functions, Activities, Participation and Environmental Factors) rating scales. Moreover, the internal consistency of these above mentioned four domains demonstrated high reliability, ranging from 0.939 (Excellent) for Activities domain, 0.917 (Excellent) for Body Functions domain, 0.841(Good) for Participation domain to 0.788 (Acceptable) for Environmental Factors domain.

Contradicting to the reliability results of the present study, the original ICF-CY based parent report questionnaire for Children with Autism (Gan et al. 2013) showed moderate to excellent agreement for majority of the items in Body Functions domain, Activities domain and Participation domain. But for Environmental Factors domain, only 46.2% of items were found to have moderate agreement whereas the rest 53.8% of the items demonstrated poor agreement. The reasons for poorer inter-rater reliability observed for majority of the items in Environmental Factors domain were attributed to the complexity of understanding the items belonging to this domain and usage of the five levels rating scale (Starrost, Geyh, Trautwein, Grunow, et al. 2008).

The probable reason for obtaining excellent agreement in all the four domains of the modified ICF-CY based parent report questionnaire for autism could be because of the

modifications made to the original questionnaire. Moreover, these modifications would have assisted the speech language pathologists in framing the questions to be asked to the parents of pre-school children with autism and eased the parents in understanding the questions asked.

The functional performance level of pre-school children with autism

Across the four domains of the modified version of the ICF-CY parent based report questionnaire, **pre-school children with autism required more assistance for longer duration in order to perform the activities from Participation domain in real life situations**. But the **least level of disability was found in the Environmental Factors domain** because of least barrier scores. The least barrier scores indicate that the Environmental Factors which were scored as barriers had hindered the child's functioning to a least extent. This finding is in consonance with the finding of the study done by Gan et al. (2013) where the authors had found that their participants performed the activities from Participation domain with highest level of difficulty and similarly, least barrier scores were observed in the Environmental Factors domain.

Among the **sub-domains of body functions domain**, the pre-school children with autism of the present study were shown to have **highest level of impairment in Voice and Speech Functions** sub-domain and the **least level of impairment in the Sensory Functions and pain sub-domain**. Among the **sub-domains of activities domain**, the participants of the present study were **more dependent in executing the activities from Learning and Applying Knowledge** sub-domain whereas they were **less dependent in executing the activities from Mobility** sub-domain. In consonance with these findings,

Gan et al. (2013) also observed that the performance level of their participants was found to be similar across the sub-domains of Body Functions and Activities.

Among the **sub-domains of participation domain**, the current study's pre-school children with autism required **more support for longer duration to perform the activities from Communicating-Conversation** sub-domain whereas they required **less support for lesser duration to perform the activities from Domestic Life/Major Life Areas** sub-domain. Gan et al. (2013) also found that their participants performed the activities from Communicating-Conversation sub-domain with highest difficulty. Unlike the participants of the present study, the activities form Interpersonal Interactions and Relationships sub-domain was performed with least difficulty.

Among the **sub-domains of environmental factors domain**, the statements from **Support and Relationships** sub-domain act as a **great hindrance** for the present study's children's participation whereas the statements from **Attitudes** sub-domain **hinders** these children's participation to a **least extent**. Since the rating scale for Environmental Factors domain was modified, there were no studies to support this finding.

Among the pre-school children with autism, their abilities and disabilities were assessed across the four domains

As mentioned earlier, the modified version of ICF-CY based parent questionnaire for pre-school children with autism provides a universal language for documenting and assessing the developing children's ability and disability associated with autism diagnosis in each of the domains namely body functions, activities and participation. For environmental factors domain, it assesses whether the factors such as products and technology, support

and relationships and attitudes completely hinders/facilitates these children's participation

The abilities and disabilities of pre-school children with autism assessed in the Body Functions domain

Table 5.1

A list of strengths and weaknesses assessed in Body Functions domain.

Abilities (No problem)	**Disabilities (severe-profound problem)**
Sleeping without disturbance	Divided attention
Taste functions	Speaking fluently without interruptions
Sensing body pain	Speaking at a normal pace
Auditory perceptions	Sustaining attention
Exhibiting discomfort to painful or uncomfortable sensations	Visual perceptions
Eye hand coordination	Touch functions
Reacting to new objects or experiences in an interested way	Completing a task with sustained effort
	Shifting attention
	Smell functions

As mentioned in the theory, Morrow. (2010) stated that children with Autism were found to have intact sustained attention skills and impaired shifting and divided attention skills. This statement contradicts to the above mentioned finding of the present study where the participants had severe-profound problem in all three attention skills such as sustained attention, divided attention and shifting attention.

Gan et al. (2013) reported that their participants had highest level of impairment in speaking with intonations. But according to the results of the present study, majority of the children had severe-profound problem in speaking fluently without interruption and at a normal pace. This is because in the present study, majority of participants' expressive

skills were limited to single words and only few were able to express simple phrases. The probable reasons for their delay in acquisition of expressive skills could be either because of their poor cognitive functions or poor imitation abilities or inadequate stimulation at home.

According to Diagnostic Interview of Communication and Social Behavior (Wing, Leekam, Libby, Gould et al. 2002), impairment in smell, taste and touch functions were considered as diagnostic symptoms of Autism. But in the present study, the participants were found to have no problem in taste functions and severe-profound problem in smell and touch functions.

The probable reasons for the participants of the present study to have severe-profound problem in completing a task with sustained effort and visual perceptions such as grouping objects based on shape, size and color could be attributed to either of their poor cognitive functions or behavioral issues.

The abilities and disabilities of pre-school children with autism assessed in the Activities domain

Table 5.2

A list of strengths and weaknesses assessed in Activities domain.

Abilities (No Difficulty/ completely independent)	**Disabilities(severe-profound difficulty/severe-profoundly dependent)**
recognizing the modifications made to one's own environment	narrating events or stories or expressing one's needs
responding appropriately to changes in usual sequence of activities/daily routines	responding to questions or instructions through actions or with words
responding to requests or commands through actions or with words	generating WH questions
throwing ball or tossing coin and catching objects	planning, initiating and making temporal and spatial arrangements in order to complete a simple task
indicating need for urination and defecation	counting and arranging numbers in ascending and descending order
protecting themselves from danger/harm/injury	using real objects/props to enact a particular event
	narrating events /requesting things verbally in a correct sentence order
	wearing socks, tying shoe lace and putting sandal buckles
	describing the object based on size, shape, length, using quantity markers (more/less) and/ recognizing the opposites
	generating a list of items for a lexical or grouping the objects with respect to its identity or its role for an activity
	using semantic relations
	reading aloud
	recognizing the letters and words
	sustaining one's focus on a specific task or event
	learning through actions by associating two or more objects
	expressing meaningful words or signs
	recognizing numbers
	wearing clothes
	using inanimate objects to enact a particular event; practising recitals

Gan et al. (2013) found that majority of children with autism were completely dependent on their care-givers for pretend play, acquiring correct syntax order and complex concepts and also for producing words, phrases and longer passages in spoken messages. They were also found to have complete difficulty in comprehending complex spoken language and generating Wh questions. The finding of this study is in consonance with the results of the present study but greater difficulties were faced by the participants of the present study in performing the activities from activities domain.

The literature reports that DSM IV (American psychiatric Association. 1994) considers lack of pretend play as a characteristic feature of autism. Wing & Gould (1979) also found that 55% of the children with autism do not engage themselves in symbolic imaginative play and also in pretend play. Therefore, the finding of the present study was in congruous with this characteristic feature of autism.

Generally, in the theory it had been reported that children with autism have poor self-care skills. Even in the present study, children with autism were more dependent on caregivers for carrying out the activities related to self-care skills.

The finding on the literacy skills of the participants of the present study was in dissonance with the finding of Loveland & Tunali-Kotoski (1997). Because these authors stated that children with autism were generally found to be good in reading and calculating numerals. But in the present study, majority of the children with autism had poor literacy skills and the reason for this may be attributed to either of their poor attention skills, memory functions and executive functions or lack of exposure for the child to acquire literacy skills (Zingerevich & La Vesser, 2009).

In consonance with the DSM IV (American psychiatric Association, 1994) criteria for autism, the participants of the present study were found to have delay in acquiring speech and language skills leading to social communication impairment. Therefore, based on the weaknesses observed in this domain, these children were found to fit into the criteria for autism.

The abilities and disabilities of pre-school children with autism assessed in the Participation domain

Table 5.3

A list of strengths and weaknesses assessed in participation domain.

Abilities (No Difficulty/ Completely independent)	**Disabilities (severe-profound difficulty/ severe-profoundly dependent)**
playing alone with toys	sustaining a conversation interacting with others independently and varying the speaking style in accordance with the recipient's role in the society responding with a sense of satisfaction and gratitude in a culturally acceptable manner playing social games with others with a shared goal or purpose rendering a helping hand in planning, organizing and managing household work and also in serving meals making a call independently taking turns in verbal group activities starting a conversation being obedient to parents and taking care of them in times of need acquiring academic skills and non-academic skills from family members or parents attending classes, interacting with peers and obeying the rules stated for students

The subjects of the present study required more support for a longer duration to start and sustain a conversation, render help in preparing meals, play social games with others with

a shared goal or purpose and also to interact with peers and obey the rules stated for students. Even Gan et al. (2013) found that their children with Autism faced profound difficulties in performing the above mentioned activities.

As stated by the conventional Autism Spectrum Disorders' (ASD) assessment tools, one of the main areas of functional deficits observed in children with Autism is social interaction. In accordance to the present study, children with autism were found to have impairment in social interaction/communication skills. The reason for this could be possibly attributed to their inability to share attention and engage themselves in symbolic play or limited expressive vocabulary or poor comprehension abilities or poor pragmatic skills (Mundy, Sigman, Ungerer & Sherman, 1986).

With respect to the play skills of the participants of the present study, majority of them had no difficulty in engaging themselves in solitary play but they required more support for longer duration to play social games with others with a shared goal or purpose. In addition to this finding, they had limited parallel and onlooker play. Their deficits in play skills other than solitary play would have possibly led to poor development of social interaction skills (Cronin & Mandich, 2015). They engage themselves more in solitary play because of their atypical play patterns. Therefore the findings of the present study with respect to play skills are in consistent with characteristics of autism.

In the present study, majority of the participants were found to be severe-profoundly dependent on others to render a helping hand in planning, organizing and managing household work and serving meals and also be obedient and take care of their parents in need. The probable reasons for these observed difficulties may be because of their limited

play or joint attention skills or inability to understand the mental representation of others or poor executive functions as stated theoretically.

Children with autism were reported to have poor executive functions (Zingerevich & La Vesser, 2009). In support of this finding, the participants of the present study were found to have difficulties in participating school activities and this could be probably because of their poor executive functions (i.e. inability to observe or plan or reason out or solve problems), joint attention and imitation skills.

With respect to the environmental factors domain, majority of the parents of pre-school children with autism reported that the mentioned below environmental factors had completely facilitated the child's functioning.

Table 5.4

A list of environmental factors which were considered as facilitators for pre-school children with autism

Playing with toys and puzzles
Accessing books, Computer and educational toys
Assistance provided by the parents, Health professionals and relatives
Positive attitude of parents such as determined to work towards the welfare of their children
Positive attitudes of health professionals such as being service oriented and skilled to handle children with Autism
Positive attitudes of relatives such as praising/motivating the child with autism for his/her achievements and Informing the parents of children with autism about any rehabilitation programs and willingness to stimulate them to speak
Positive attitude of peers such as inviting children with autism in social gatherings
Positive attitudes of society such as providing a comfortable environment for children with autism to socialize with others, accepting them as part of their society and positively engaging them in festival celebrations

In dissonance with this finding, Gan et al. (2013) found that products of play and education, support provided only by parents and health professionals and attitudes of

parents, relatives, peers, teachers and health professionals were considered as facilitators for their participant's functioning.

A small percentage of the caregivers of the present study had scored the products of play and education, support provided by relatives and neighbors, negative attitudes of parents, relatives, peers, teachers, society and health professionals as severe to profound barriers. A small percentage of them had also scored the positive attitudes of relatives, peers, teachers, health professionals and society as severe barriers for their children's functioning. In contradicting to the present study, Gan et al. (2013) indicated that a small percentage of the caregivers reported that support provided by parents and extended family members and the attitudes of society and extended family members were considered to be severe-complete barriers for their children's functioning.

Overall, the modified version of ICF-CY based parent report questionnaire for autism was found to demonstrate the functional characteristics of pre-school children with Autism. Therefore documenting the weaknesses of children with autism observed in these domains such as body functions, activities and participation domains would assist the speech language pathologists in the selection of goals and also in reducing the severity level of their disabilities/impairments. Furthermore the information obtained from environmental factors domain would assist the clinicians in identifying and overcoming the barriers in order to facilitate the child's performance level.

Based on the **correlation analysis of the present study**, **the difficulties on the activities or participation level faced by pre-school children with Autism were influenced by problems in one's own body functions** and not by environmental factors. Contradicting the results of the present study, Gan et al. (2014) found that

difficulties on the activities or participation level faced by pre-school children with Autism were influenced strongly by problems in one's own body functions and weakly by the environmental factors. Henceforth, with respect to the results of the present study, the problems in Body Functions had majorly impacted the participation of Pre-school children with autism.

CHAPTER VI

SUMMARY AND CONCLUSIONS

The conventional Autism Spectrum Disorders' (ASD) assessment tools namely Autism Diagnostic Observation Schedule, Autism Diagnostic Inventory Revised and Childhood Autism Rating Scale failed to measure the influence of specific environmental factors on participation and account the specific and individualized aspects of the child's participation in real life situations in a common language that can be comprehended across various disciplines. These traditional assessment tools mask the functional disparities within the same diagnosis and this imposes challenge on intervening children with ASD. They document only the deficits observed in children with Autism but they fail to account for the strengths which influence their overall functioning. These ASD assessment tools may assist the speech language pathologists in confirming the diagnosis but the structured nature of these tools restrict the health professionals to individualize the intervention process.

To overcome the pitfalls of traditional ASD assessment tools, an ICF-CY based parent report questionnaire for Pre-school children with Autism was developed. The ICF-CY based parent report questionnaire for Pre-school children with Autism aimed to provide a universal framework for the health professionals to identify specific characteristics of functioning within the triad deficit areas, assess the developmental aspects of each child functioning in real life situations and also the impact of specific environmental factors on participation. Thus it helps in classifying the disability in terms of four domains body functions, activities, participation and environmental factors. With the help of qualifiers,

the speech language pathologists can rate the severity of the impairment within the four domains.

Since there is no literature to support the use of ICF-CY based assessment tool for Pre-school children with autism in Indian context, the present study aimed to suitably modify the Taiwanese based ICF-CY questionnaire for Autism and administer it to 20 care-givers of Indian Pre-school children with autism.

The study was carried out in two phases.

In **phase 1**, the neutral statements were framed for the 26 adapted items of body functions domain, 40 adapted items of activities domain and 18 adapted items of participation domain. In the last domain that is the environmental factors domain, the neutral statements were framed for the two adapted items of products and technology sub-domain and four adapted items of support and relationships sub-domain. In addition to this, six neutral statements (where 3 statements conveyed positive attitudes and the other three conveyed negative attitudes) were framed for each of the adapted six items (such as parents' attitudes, individual attitudes of extended family members, peers' attitudes, teachers' attitudes, health professionals' attitudes and societal attitudes) of attitude sub-domain. On the whole, the modified ICF-CY based Parent Report Functional assessment tool for Autism consisted of one hundred and twenty six neutral statements. These framed neutral statements were sensitive to assess impairments of body functions, activity limitation, and participation restriction and also to identify the environmental barriers and facilitators. The activities which were relevant to 3 to 6 year old children with autism

were mentioned in the illustrations for each statement for the ease of parents in understanding the questions asked.

Then, the items of the questionnaire were validated and the items which were rated as fairly understandable were modified. The ICF-CY qualifier scoring scale was framed for each of the four domains namely Body functions, Activities, Participation and Environmental factors. Then, the reliability of the modified ICF-CY questionnaire for pre-school children with autism was assessed and found to be more reliable than the ICF-CY based parent report questionnaire for Children with Autism developed by Gan et al. (2013).

In the **phase 2**, the functional performance level of 20 Indian pre-school children with autism was assessed by using the modified ICF-CY based questionnaire. The results of the descriptive statistics indicates that pre-school children with autism required more assistance for longer duration in order to perform the activities from participation domain in real life situations since they were found to have highest level of disability in participation domain whereas the least level of disability was found in environmental factors domain because of least barrier scores. Based on the correlation analysis, the difficulties on the activities or participation level faced by pre-school children with autism were influenced by problems in one's own body functions and not by environmental factors.

The modified version of ICF-CY based parent report questionnaire for pre-school children with Autism was found to demonstrate the functional characteristics of pre-school children with autism. Thus it provides a universal language for documenting and assessing these children with impairment of body functions, activity limitation and

participation restriction and also for identifying the facilitators and barriers for the child's functioning. It had also measured the participants' ability and disability associated with the autism diagnosis. Since it is compatible with conventional ASD diagnostic tools, it can identify the uniqueness of each child with respect to functioning aspects. It also helps in setting goals in a common language focusing on adaptation of tasks, provision of environmental facilitators and removal of environmental barriers that interfere with the child's ability to communicate in their home and communities. Thus it is helpful in implementing an individualized intervention program.

Limitations of the study

1) The modified questionnaire was administered on a small sample size

2) Since the modified questionnaire was in English, some items may not be relevant to Indian languages and culture

3) Since the modified questionnaire comprised of 126 neutral statements, administering the questionnaire becomes very time consuming

4) Age, gender and severity group comparisons were not investigated

Implications for future research

1) The modified ICF-CY based parent report questionnaire was administered on a small sample and so it can be administered on a large sample of children with autism for validating this questionnaire.

2) Since it can be used to chart the developmental changes in functional aspects of children with autism, age group differences (3 to 4 years; 4 to 5 years; 5 to 6 years) can be investigated in terms of functional aspects across the four domains.

3) This questionnaire can be translated to different Indian languages and while translating, the items can be modified because some of the items may not be applicable to some Indian languages/culture.

4) The modified version of ICF-CY based parent report questionnaire can be administered to investigate the efficacy of using this questionnaire for charting the intervention progress for children with Autism.

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APPENDIX - I

Domain 1- Body Functions

Instructions - To assess the severity of impairment in body functions domain for pre-school children with Autism, the mentioned below statements should be rated with respect to the formulated body function domain's scoring scale. Kindly go through the illustrations for each statement in order to ease the understanding of the parents/care-givers of pre-school children with Autism

Scoring 0 – No Difficulty; 1- Mild Difficulty; 2- Moderate Difficulty; 3- Severe Difficulty; 4 – Profound Difficulty

Mental Functions

b1250	Ability to act or react in an interested way to new objects or experiences (e.g. shows interest in seeing new toys or enjoys going to new places such as park, circus or relative's house)
b1252	Ability to involve actively in an activity (e.g. playing theme games such as house-house or tea party games or outdoo or puzzles or singing action rhymes actively with interest)
b1254	Ability to complete a task with sustained effort (e.g. building a tower or tying shoe lace or completing a puzzle with sustained effort)
b1342	Ability to sleep for 8-9 hours without disturbance
b1400	Ability to sustain attention in an activity (e.g. putting small beads through the string or paying attention to what is been taught or colouring the pictures within the picture's boundary or making something out of dough which represents a referent)
b1401	Ability to refocus attention from an object/activity to another object/activity (e.g. shifting attention from the toy which the child is playing with to another new toy introduced by his/her parents or ability to stop playing with his/her toy when he/she is asked to follow simple commands such as give me car from the choice of two or three items put in front of them)
b1402	Ability to respond to more than one task simultaneously (e.g. watching T.V. while playing a building block game or answering to mother's question (e.g. what sound does train make?) while playing with his/her toy)

b1403	Ability to attend to an object when it is been described by the caretaker (e.g. paying attention to an object when it is being talked about or looking at a picture book when the caregiver describes those pictures in that book or doing a puzzle with the caregiver)
b1440	Ability to recall the learnt information (e.g. alphabets/colours/ nouns/ verbs etc) when asked after 30 secs
b1441	Ability to recall the learnt steps to follow a particular routine Ability to recall the learnt concepts such as names of colours, alphabets, counting numbers
b1520	Ability to express feelings in accordance with the situation (e.g. feels happy when his/her family members comes home or feels sad when everyone is sad at home or when someone gets hurt)
b1521	Ability to control the urge to engage in impulsive behaviors, self-harm, reckless behavior, or physical aggression when distressed
b7653	Ability to control restricted repetitive non-purposive behavior such as repetitively rocking back and forth and nodding the head or wiggling

Sensory Functions and Pain

b1560	Ability to discriminate loud vs soft sounds and pleasant vs unpleasant sound (e.g. closing the ears when he hears loud noise or enjoys listening to songs when played softly)
b1561	Ability to group the objects based on shape, size and color (e.g. grouping all the red color objects or objects of small size etc)
b1565	Ability to turn towards or track an object when it's location (prepositions) and distance (Far/ near etc) is described
b2801	Ability to sense pain or discomfort felt in a specific part of the body (e.g. Cries by pointing to a specific part of the body in order to express pain)
b250	Ability to recognize the taste differences (e.g. enjoys when he/ she eats sweet food or spits out when he/she eats bitter food or asks for/ drinks water when he/she eats spicy food)
b255	Ability to sense pleasant and unpleasant odor (e.g. holding the nose or showing signs of discomfort when he smells a bad odor)
b265	Ability to sense and recognize the difference based on the objects texture (hard/ soft etc) (e.g. pointing to a hard object when asked to)
b2703	Ability to sense painful or uncomfortable sensations (e.g. showing discomfort when listening to loud music or sensitive to bright lights or showing unpleasant reactions to unpleasant taste or smell)
b279	Ability to handle or manipulate objects (e.g. building blocks, playing puzzle, catching ball, putting beads through the thread or tying shoelace)

Voice and Speech Functions

b320	Ability to articulate speech sounds (p,b,t,d,g,k,f,v,s,z,ch,j,y,r,sh)
b3300	Ability to speak fluently without any interruptions (MLU: 3-4 0r 4-5 words/utterance)
b3302	Ability to speak at a normal pace
b3303	Ability to speak (vocalizations/ true words along with jargon utterances /meaningful verbal utterances) with intonation (e.g. lowers the pitch to express sadness or raise the pitch to express happiness or surprised)

Domain 2 - Activities

Instructions - To assess activity limitation i.e. difficulty level in executing the tasks independently, the formulated activities domain's scoring scale should be used to rate the below mentioned statements. Kindly go through the illustrations for each statement in order to ease the understanding of the parents/care-givers of pre-school children with Autism

Scoring 0- No Difficulty (completely independent); 1- Mild Difficulty (Slightly independent); 2- Moderate Difficulty (Fairly independent); 3- Severe Difficulty (Extremely dependent); 4- Profound Difficulty (completely dependent)

Learning and Applying Knowledge

d130	Ability to imitate speaker's facial expression or verbal expression or non-verbal expression (such as imitating other's facial expressions, gestures/actions of the doers, sounds or alphabets or numbers or true words or phrases)
d1311	Ability to learn through actions by associating two or more objects which are used to perform a particular event (e.g. soap, mug and towel - bathing, spoon and plate - eating, fruits, juicer and spoon- juice making or spoon, plate and pan- cooking)
d1314	Ability to use inanimate objects to enact a particular event (Pretend play) (e.g. pretending that a block of wood is a car, pretending that a rolled up cloth is a doll etc)

d1313	Ability to use real objects/props to enact a particular event (e.g. playing tea party game with the dolls, doctor patient game, Pretending to talk on the phone)
d1330	Ability to express meaningful words
d1331	Ability to use semantic relations (two word combinations) (e.g. agent+action (amma brushing), action+object (give cup), No + object (no toy))
d1332	Ability to describe or narrate events or request things verbally in a correct sentence order (e.g. SVO or SOV pattern with respect to language spoken)
d135	Ability to practise recitals (e.g. reciting rhymes with actions, saying alphabets and counting numbers)
d1370	Ability to describe the object based on size, shape, length, use quantity markers (more/less) and recognize the opposites (e.g. saying big ball by looking at it or requesting for more bikis, pointing to a clean and dirty shirt when asked to)
d1371	Ability to generate a list of items for a lexical or group the objects with respect to its identity or its role for an activity (e.g. asking the child to name five fruits or group the red colored objects or pointing to objects which are used to perform an action (bathing))
d1400	Ability to recognize alphabet letters and words
d1401	Ability to read aloud the letters and words
d1500	Ability to recognize numbers
d1501	Ability to count numbers and arrange numbers in ascending or descending order
d1600	Ability to identify or recognize the features of other persons such as their face, touch or voice
d1601	Ability to recognize the modifications made to one's own environment (e.g. Modifications made with respect to features/ location of the objects or changes in the room set-up or inclusion of new people in the house)
d161	Ability to sustain one's focus on a specific task or event

General task and demands

d2100	Ability to plan, initiate and make temporal and spatial arrangements in order to complete a simple task (e.g. quick cleaning, quick purchase, quick arrangement of toys, books etc)
d2300	Ability to engage in daily activities in correct sequence with caregiver's support
d2304	Ability to respond appropriately to changes in usual sequence of activities/daily routines (e.g. adjusting to new requirements such as keeping an object not in the usual place or to new sequence of daily routines or modifying the existing habits or rules (taking another route to school etc))

Communicating-Receiving

d3101	Ability to respond to requests (e.g. give me) or commands (e.g. no, come here) through actions or with actions
d3102	Ability to respond to questions (what, where, which, when, yes/no) or instructions through actions or with words
d3150	Ability to interpret the message conveyed by facial expressions, hand movements and body postures
d3350	Ability to convey meaning through facial expressions, gestures and postures such as pointing or display of affect (e.g. smiling and embracing to indicate affection or frowning to express anger or expressing their needs through pointing or pointing to something to gain attention from the care-givers)
d330	Ability to describe, narrate events or stories or express his/her needs verbally
d331	Ability to generate Wh questions to seek specific information about person, things and events

Mobility

d440	Ability to perform a sequence of actions with an object using hands (such as picking up, manipulating and releasing them using one's hand, fingers and thumb e.g. coins off a table or turning a dial or knob)
d4454	Ability to throw ball or toss a coin
d4455	Ability to catch objects

Self-Care

d5100	Ability to pour water and apply soap to specific gross and fine body parts when asked to
d5101	Ability to pour water and apply soap to whole body
d5201	Ability to give importance to dental hygiene (brushing)
d53000	Ability to indicate need for urination
d53001	Ability to get into the proper position, choose and get to an appropriate place for urination, manipulate clothing before and after urination and clean oneself after urination
d53010	Ability to indicate need for defecation
d53011	Ability to get into the proper position, choose and get to an appropriate place for defecation, manipulate clothing before and after defecation, and clean oneself after defecation
d5400	Ability to wear clothes, gloves, put the shirt buttons and zip the pant
d5402	Ability to wear socks, tie shoelace and put sandal buckles

d550	Ability to eat in appropriate and culturally acceptable manner (i.e. table manners)
d571	Ability to protect oneself form danger/harm/injury (e.g. not playing with match sticks or running into traffic or keeping his/her hand into the pedestrian fan etc)

Domain 3 - Participation

Instructions - To assess the level of participation restriction i.e. the independency level of the child with Autism in executing the tasks in real life situations, the below mentioned statements should be rated with respect to the formulated participation domain's scoring scale. Kindly go through the illustrations for each statement in order to ease the understanding of the parents/care-givers of pre-school children with Autism

Scoring 0- No Difficulty (completely independent); 1- Mild Difficulty (Slightly independent); 2- Moderate Difficulty (Fairly independent); 3- Severe Difficulty (Extremely dependent); 4- Profound Difficulty (completely dependent)

Communicating - Conversation

d3500	Level of support and the duration of assistance required for the child to introduce oneself (V/NV) or a topic or ask questions or greet people voluntarily
d3501	Level of support and the duration of assistance required for the child to sustain a conversation by adding ideas related to the main topic or introduce a new topic or retrieve a topic that has been previously mentioned
d3600	Level of support and the duration of assistance required for the child to make a call independently

Interpersonal Interactions and Relationships

d7101	level of support and the duration of assistance needed for the child to show or respond a sense of satisfaction and gratitude in a culturally acceptable manner (saying thank-you politely, showing respect, saying sorry if he/she hurts someone etc)

d7109	Level of support and the duration of assistance required for the child to take turns in group activities (V)
d7105	Level of support and the duration of assistance needed for the child to embrace close family members and higher authorities in a socially acceptable manner (e.g. maintaining a proper distance with higher authorities or not hugging family members in public for no reasons)
d7203	Level of support and duration of assistance needed for the child to interact with others independently and vary the speaking style in accordance with the recipient's role in the society
d7601	Level of support and duration of assistance required for the child to be obedient to parents and taking care of them in times of need
d7602	Level of support and duration of assistance required for the child to share a friendly bond with siblings
d7603	Level of support and duration of assistance required for the child to share a friendly bond with cousins, aunts and uncles and grand parent

Domestic Life/Major Life Areas

d6302	Level of support and duration of assistance required for the child to render a helping hand in serving meals
d6406	Level of support and duration of assistance required for the child to render a helping hand in planning, organizing and managing household work
d810	Level of support and duration of assistance required for the child to acquire academic and/ non-academic skills from parents or family members (e.g. academic skills - counting objects, recognizing alphabets and numbers, reciting rhymes and naming colours and non- academic skills - crafts, drawing and colouring)
d8151	Level of support and duration of assistance required for the child to attend classes, interact with peers and obey the rules stated for students
d8800	Level of support and duration of assistance required for the child to play alone with toys
d8801	Level of support and duration of assistance required for the child to observe the action of others with play material without joining them
d8802	Level of support and duration of assistance required for the child to engage in activities with toys or games in the presence of others without joining them
d8803	Level of support and duration of assistance required for the child to play social games with others with a shared goal or purpose

Domain 4 - Environmental Factors

Instructions - The mentioned below statements should be rated with respect to the formulated scoring scale for environmental factors domain. The scoring for environmental factor domain will indicate whether the statements from products and technology and support and relationships sub-domains act as a barrier or a facilitator for the child's participation in relevant life situations. The environmental factor could be a barrier either because of unavailability of a required service/assistance or assistance/service provided does not facilitate the child's behavior.

Scoring 0- No Barrier; 1-Mild Barrier; 2- Moderate Barrier; 3 – Severe Barrier; 4 – Profound Barrier

Products and Technology

e11520	Playing with toys and puzzles influences the child's behaviour
e1300	Accessing books, educational toys and computer influences the child to acquire knowledge

Support and Relationships

e310	Assistance provided by the parents influences the child's behaviour (e.g. Able to stimulate the child at home in spite of over burden of household work etc)
e315	Assistance provided by child's relatives (cousins, aunts, uncles) influences the child's behaviour (e.g. Being a facilitator for the child to improve his/her functional communication skills etc)
e320	Assistance provided by peers and neighbours influences the child's behaviour (e.g. Peers - Rendering a helping hand in school work/ while playing games/ eating Neighbours - Being a facilitator for the child to improve his/her functional communication skills etc)
e355	Support provided by health professionals influences the child's behaviour (e.g. giving home training program to the parents)

Attitudes

Instructions - The environmental factor can be a barrier because of negative attitudes towards children with Autism. Not applicable can be mentioned if the family members/ extended family members/ peers/ teachers/ health professional/ society do not express the negative attitudes which are mentioned in statements such as e410A-e410C, e415A-e415C, e425D-e425F, e455A-e455C, e450A-e450C and e460A-e460C.

e410: Strong attitudes of immediate family members (parents and siblings) mentioned below influences the child's behavior

e410A	Being protective (e.g. Regulating the child's behavior without allowing the child to think about the next move while playing games or performing daily activities)
e410B	Being frustrated (e.g. Showing anger or hatred or frustration towards the child)
e410C	Feeling anxious or uncertain about the child's future
e410D	Determined to work towards the welfare of the child (e.g. enrolling the child for speech therapy classes and in school, facilitating the child to communicate at home)
e410E	Well-adjusted by the siblings to the changes in the family routines (e.g. Not being jealous because of limited parental attention)
e410F	Siblings permit them to socialize with others (e.g. Facilitating them to play with their friends)

e415: Strong attitudes of extended family members (uncles, aunties, cousins) mentioned below influences the child's behavior

e415A	Isolation (e.g. Prohibiting them from playing with their children)
e415B	Child's cousins dominate over them
e415C	Being hostile (Being unfriendly with the child)
e415D	Willingness to stimulate the child to speak
e415E	Praising/motivating the child for his/her achievements
e415F	Informing the parents of children with autism about any rehabilitation programs for the welfare of the child

e425: Strong attitudes of peers mentioned below influences the child's behavior

e425A	Willingness to make friends
e425B	Including the child in social gatherings such as birthday Parties, picnic etc
e425C	Sharing their toys /things
e425D	Teasing
e425E	Scared to interact
e425F	Not including the child in outdoor / indoor games because it exerts increased mental abilities and physical demands for a child with autism

e455: Strong attitudes of teachers mentioned below influences the child's behavior

e455A	Unwillingness to enroll the child in mainstream schools
e455B	Underestimating the child's capabilities
e455C	Not appointing caretakers to assist the child in his/her class work
e455D	Making the content simple for the child to understand
e455E	Making an attempt to find out through which modularity (auditory/ visual) the child learns and responds faster
e455F	Praising the child for his/her attempts to respond

e450: Strong attitudes of health professionals mentioned below influences the child's behavior

e450A	Lack of coordinated effort among the professionals (SLT/OT/PSYC) in rehabilitating the child due to ego issues
e450B	Being money minded by misguiding the parents of child with autism in availing the services
e450C	Instilling over-expectations in the minds of parents about the child's progress
e450D	Service oriented
e450E	Skilled enough to handle the child with autism (e.g. finding out through which modularity (auditory/ visual), the child learns and responds faster)
e450F	Taking an initiative in educating the society, teachers and peers about the child's status

e460: Strong attitudes of society mentioned below influences the child's behavior

e460A	Offending the child by passing disparaging remarks
e460B	Not allowing their children to mingle
e460C	Thinking of children with autism as a burden/ inconvenience/ nuisance to the society since they are economically unproductive

e460D	Positively engaging the child in festival celebrations in order to make the child to be aware of these celebrations
e460E	Providing a comfortable environment for the child to socialize with others
e460F	Accepting the child as part of their society