

## Original Research Paper

# ICF - Based Analysis of Parents' Perception of Difficulties faced by Children with Learning Disabilities

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## ABSTRACT

**Background:** The International Classification of Functioning, Disability and Health for children and adolescents (ICF CY) framework is used for evaluating domain specific difficulties in children with Specific Learning Difficulties (SpLDs). **Aim:** The aim was to profile the communication-related activity limitation and participation restriction if any, in children with LD using the ICF framework based on parental report. **Method:** 35 parents of children with academic difficulties were interviewed with the ICF CY checklist aimed to estimate the functioning profile of the children with respect to communication related activities in their environment and get an overview about any participation restriction posed by their specific learning disabilities. **Results:** The results of the present study revealed that majority of CWLD, do not have much difficulty in understanding verbal or gestural instructions, nor do they have any problems in speaking still they were unable to maintain social relationship. When it comes to reading, writing and performing calculations, they do face problems of varying severity. While the traditional assessment does tap the specific difficulties in reading and writing, ICF CY complements the traditional diagnosis by emphasizing not only what impairment is seen in an individual but also giving directions in terms of what social factors should be considered when selecting appropriate goals to bring about change in the lives and in the school experiences of children with LD. It gives important cues to parents that not only outside but the situation in child's own home also needs modification. **Conclusion:** ICF CY serves as a tool for advocacy of inclusion of children with LD in various situations like school, home and society at large. The use of parental report provide insight to parents about the difficulties faced by their children and provide them with the opportunities to work together with the therapist not only to provide direct intervention with the child, but also to be instrumental in creating awareness about the needs of their children among his friends, school and society.

**Key words:** ICF CY, learning disabilities, Parental report, difficulty domains

## INTRODUCTION:

Learning disability is a multi-dimensional disorder. Children with learning disability may experience significant reading problems, while another may experience no reading problems whatsoever, but has significant difficulties with written expression. Some other may show difficulty in calculations or have memory and visuo-perceptual deficits. Yet others may have difficulty at very basic phonemic level. Children

may present with single or combination of these deficits. This multifaceted disorder in functioning lead to poor self-image and children find it increasingly difficult to adjust to the fast-paced environment around them. Specific LD is also known to cause psychological and mental stress not only in the children but also among the parents (Mogasale et al, 2012). Traditional assessments used in speech language pathology do not capture the difficulties faced by CWLD in all the

domains. This deficiency, however, can be overcome by using the analysis based on International classification of functioning (ICF). The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability. This framework premised on the bio-psychosocial model that was endorsed by the World Health Organisation (WHO) in 2001 to give a comprehensive perspective of health and functioning of an individual. ICF-CY (WHO, 2007) is an adapted version of the ICF (WHO, 2001), designed to incorporate characteristics of the developing child and the influence of the surrounding environments. It provides a common and standard language and a framework for the description of health and health-related states to facilitate the documentation and measurement of health and disability in child and youth populations (WHO, 2007). In other words, ICF – CY describes how the children and youth function in the society given their health status. The ICF-CY is thus a bio-psycho-social model of functioning, which conceptualizes functioning and disability as the outcome of complex interactions between health conditions and contextual factors (environmental and personal factors).

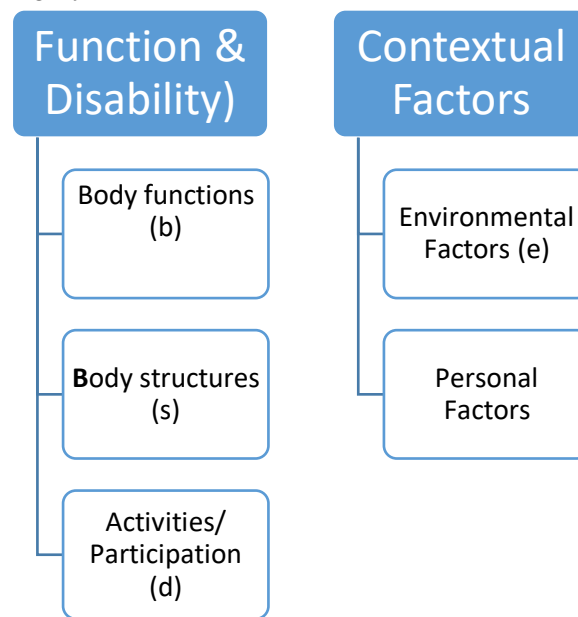
**The ICF – CY frame work:**

Like ICF, the ICF-CY framework, is a hierarchical framework consisting of two parts: (1) Functioning and Disability and (2) Contextual Factors. These parts are further subdivided into components as given below: Functioning and Disability contains two components: Body Systems (Function and Structure) and Activities/ Participation. Contextual Factors also contains two components (Environmental and Personal). These components are defined as follows (WHO, 2001; WHO, 2007):

- Body functions: Physiological functions of body systems (including psychological functions)
- Body structure: Anatomical parts of the body, such as organs, limbs and their components
- Activity: The execution of a task or action by an individual
- Participation: Involvement in a life situation
- Environmental factors: Physical, social, and attitudinal environments in which people live and conduct their lives
- Personal factors: The background of an individual’s life and living, they comprise features of the individual that are not part of a health condition or health state.

The Components of ICF CY are presented in Figure 1. Each component is further divided into domains and categories. Additionally, each of the ICF category is assigned a code, using alphanumeric notation: commencing with ‘b’ for body functions, ‘s’ for structure, ‘d’ for domain (referring to domains of the Activities/Participation component and ‘e’ for

environment. The first digit represents the domain number, the next two digits represent the (second level) category number. Two additional digits are applied for category subdivision at the third and fourth levels.



**Figure1: Components of ICF**

In addition to category codes, the ICF uses qualifiers, without which ‘the codes have no inherent meaning’ (WHO, 2001, p. 222). The qualifiers are numeric descriptors which appear following a point after the code, and there can be more than one qualifier. Eg: ‘b’ represents body functions, within that b1 represents mental functions, b 175 represents mental functions specific to language. b175.3 indicates severe deficits in mental functions specific to language. In contrast to ICIDH, WHO1980, which was based on medical model, ICF represents the shift of conceptual framework incorporating/ considering the contextual factors which facilitates / hinders the functioning of the individual. ICF does not label the disability or health condition, it just explains how the disability, or the health condition affects persons activities and participation in social life. Moreover, the ICF CY allows explanation of the entire health spectrum. One end of the spectrum being healthy body structure, body functions, activities and participation and the other end of the spectrum describes the impairments, activity limitations and participation restrictions. According to Nadine (2009), the comprehensive view of health and common language offered by the ICF framework is useful for guiding clinical and research practices within speech-language pathology. Riva and Antonietti (2010), based on a single case study demonstrated the clinical usefulness of application of ICF-CY for children with specific learning disabilities. They showed how the multi-fold nature of LD and its effect on various life domains can be captured better with the application of ICF- CY model. The aim of the current study was to profile the communication-related activity limitation and

participation restriction if any, in children with LD using the ICF framework based on parental report.

**METHOD**

**Participants:** 35 parents of children in the age range of 8 to 13 years (mean age: 11years 2 months) and diagnosed as having LD who were a part of a larger study. The diagnosis of LD was based on Woodcock Johnson Test or Curriculum Based Test as assessed by clinical psychologists. Parents were administered the ICF checklist in a face-to-face interview by the researcher after obtaining parental consent to participate in the study. For those parents who did not understand English, the items in the checklist were translated in Marathi or Hindi as per individual needs. Parents of children with communication disorders other than learning disabilities or any other neurological deficits were excluded from the study.

Parents of children having LD who were attending therapy or remedial education classes were also excluded.

**Tool:** In children with LD, there is no physical disability, but functioning, activities and participation, and environmental factors do pose concerns. Based on the metanalysis of studies done using ICF, the Washington group, looked at the domain which were used by atleast one study. They identified total of 70 areas which were mentioned in various studies.

**Table 1. Distribution of the percentage of participants with various levels of activity limitations and participation restriction across the domains tested**

Sr. No	Domain	1 Never	2 Rarely	3 Sometimes	4 Mostly	5 Always
<b>D1. LEARNING AND APPLYING KNOWLEDGE</b>						
1	d133. Does _your child have any problems using words, phrases or sentences?	55	5	25	10	5
2	d137. Does ____ have any problems with concepts such as amount, length, the same or different?	40	0	30	15	15
3	d140. Does ____ have any problems learning to read?	5	15	20	40	20
4	d145. Does ____ have any problems learning to write?	5	15	30	30	20
5	d150. Does ____ have any problems learning to calculate?	5	5	25	30	35
6	d166. Does ____ have any problems reading?	5	20	35	15	25
<b>D 3. COMMUNICATION</b>						
7	d310. Does ____ have any problems understanding what others say?	40	30	20	5	5
8	d315. Does ____ have any problems understanding the meaning of gestures or pictures?	55	20	10	15	0
9	d330. Does ____ have any problems speaking?	70	10	15	5	0
10	d331. Does ____ have any problems making different vocal sounds?	80	10	5	5	0

Based on their findings, 22 items from activities and participation section, which were relevant for children with LD were selected to make a checklist. (Appendix-1)

The checklist covered the following domains:

1. Learning and applying knowledge (d1): 6 items were included
  2. Communication (d3): 5 items
  3. Self-care (d5): 5items
  4. Domestic life (d6): 1 item
  5. Interpersonal interactions and relationships (d7): 2 items
  6. Major life areas (d8): 2 items
  7. Community, social and civic life (d9): 1 item

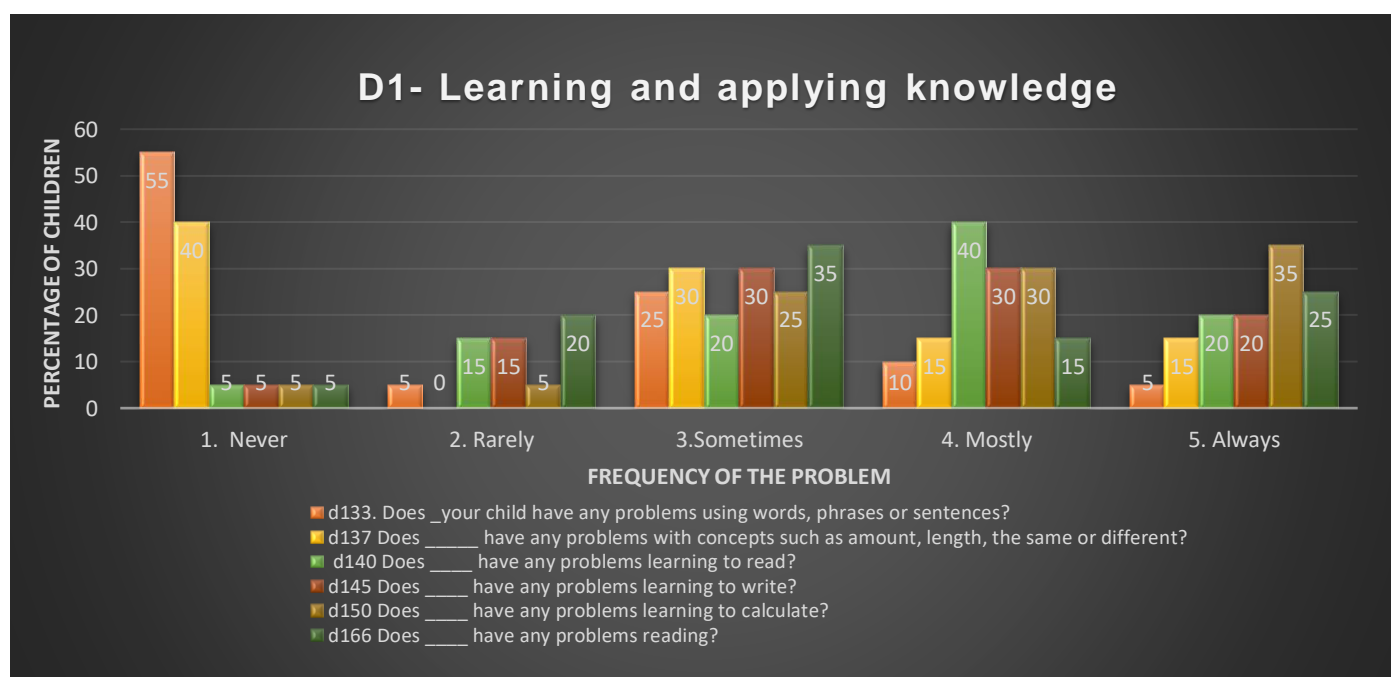
The responses obtained on each of the 22 items in the checklist was scored using a 5-point rating scale where 1 = never, 2 = rarely, 3 = sometimes, 4 = mostly and 5 = always. Information about all the items were obtained from parent reporting. The checklist can be administered in approximately 20 min. The responses obtained were tabulated and percentage analysis was done.

Thirty -five participants who met the selection criteria and whose responses to the questionnaire were complete in all aspects were analysed. Table 1 shows the percentage of children having problems of varying severity across the domains tested.

11	d335. Does ____ have any problems gestures, pictures or drawings to communicate?	40	30	25	5	0
<b>D 5. SELF CARE</b>						
12	d510. Does ____ have any problems washing self?	75	15	0	10	0
13	d530. Does ____ have any problems using the toilet?	80	10	5	0	5
14	d540. Does ____ have any problems dressing self?	75	20	0	5	0
15	d550. Does ____ have any problems eating?	85	5	10	0	0
16	d565. Does ____ have any problems avoiding harm to self?	85	0	0	15	0
<b>D 6. DOMESTIC LIFE</b>						
17	d6. DOMESTIC LIFE Does ____ have any problems participating in the activities of the household?	50	15	10	25	0
<b>D 7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS</b>						
18	d710. Does ____ have any problems relating to others?	30	20	40	10	0
19	d720. Does ____ have any problems in forming and keeping social relationships?	30	20	30	10	10
20	d817. Does ____ have any problems participating in school education?	30	0	30	25	15
21	d860. Does ____ have any problems in using money?	40	15	5	20	20
<b>D 9. COMMUNITY, SOCIAL AND CIVIC LIFE</b>						
22	Does ____ have any problems have engaging in activities in school, neighbourhood or community?	35	20	25	15	5

As seen from the table above, Domain-1 Learning and Applying Knowledge had 6 questions. Of the six questions, first 2 questions pertained to expression and

concept formation respectively. Remaining 4 questions tap the difficulties faced while learning to read, write, calculate as well as current reading ability.

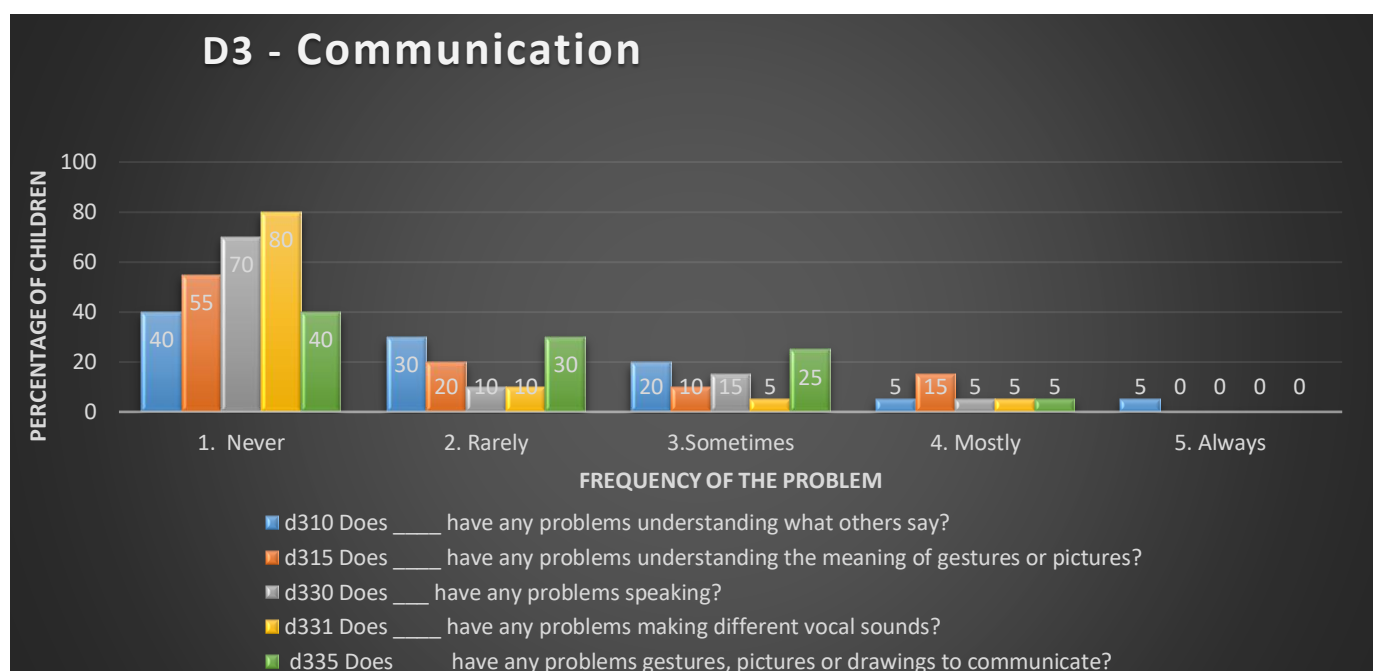


### Graph 1: Percentage of children showing difficulty in D1 Domain - Learning and applying knowledge

Majority of the parents reported that their children faced problems at least sometimes in all the areas under this domain. Analysis of results revealed, that the first two questions d133 and d137 where the only two questions where 55 and 40% of the parents respectively, reported that the children do not have any problems with understanding the concept of amount and length in terms of more or less and big or small as well as identifying the similarity and differences in objects. They also used of words related to the concept of amount, length and same or different in their oral communication. Remaining children did face problems in understanding and /or use of words related these concepts even though they were older children. With regards to learning to read (d140), 40 % children were

reported to have the problems most of the time and another 20% had it always. At the time of the study, 35% of them had problems in reading (d166) most of the time and 25% of children were reported to always face difficulty in reading. Barring 5% of the children, all of them were reported to have had problems in learning to write. 30% each were reported to have the problems in learning to write sometimes and mostly with another 20 % of them reported the problem in learning to write always being there.

**Domain – 3 Communication:** This domain had 5 questions. Of the 5 questions, 2 questions were related to the understanding of verbal and gestural messages. And the rest 3 questions were related to the production of vocal, verbal and gestural messages.



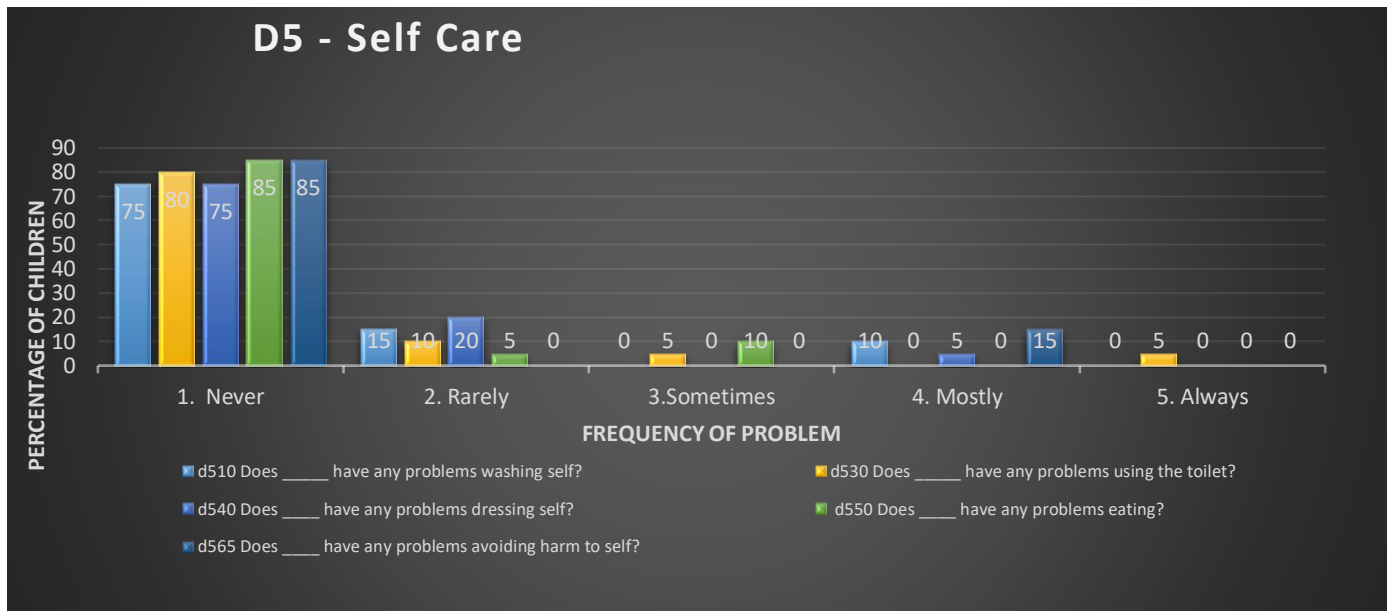
Graph 2: Percentage of children showing difficulty in D3 Domain - Communication

As seen from the graph 2, majority of the children (40%) had never presented with the problems in understanding what others say(d310). 30% had it rarely, 20% had difficulty sometimes and only 5% each reported this difficulty to be mostly or always present. Similarly, 55% of children never had problems in understanding the meaning of gestures or pictures. 20% had it rarely and 10% sometimes and 15% faced difficulty most of the times. A whopping 70 and 80% of the children never had problems in speaking or making different vocal

sounds (d330, d331). 25% of children sometimes and 30% of the children rarely faced difficulty in making use of gestures, pictures or drawings for communication (d335). Only 5% of the children always faced difficulty in all the areas tested under this domain.

**Domain - 5 Self-care:** This domain included 5 questions about self-care. it covered areas of self-help cleaning, dressing, eating as well as avoiding harm to self.

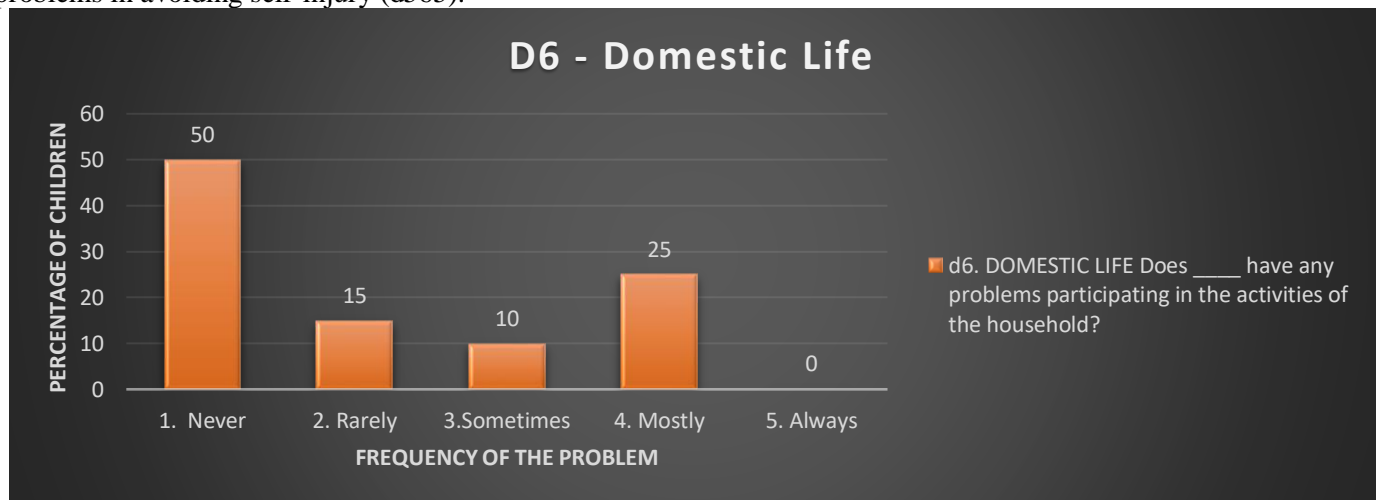




**Graph 3: Percentage of children showing difficulty in D5 Domain - Self Care**

As seen from the graph above, 75 % to 85% of the children never faced difficulty in self-care. 15% rarely and 10% mostly demonstrated difficulty in washing self (d510). Another 20% of the children rarely and 5% of them mostly faced difficulty in self-dressing skills (d540). Surprisingly 15% of the children mostly had problems in avoiding self-injury (d565).

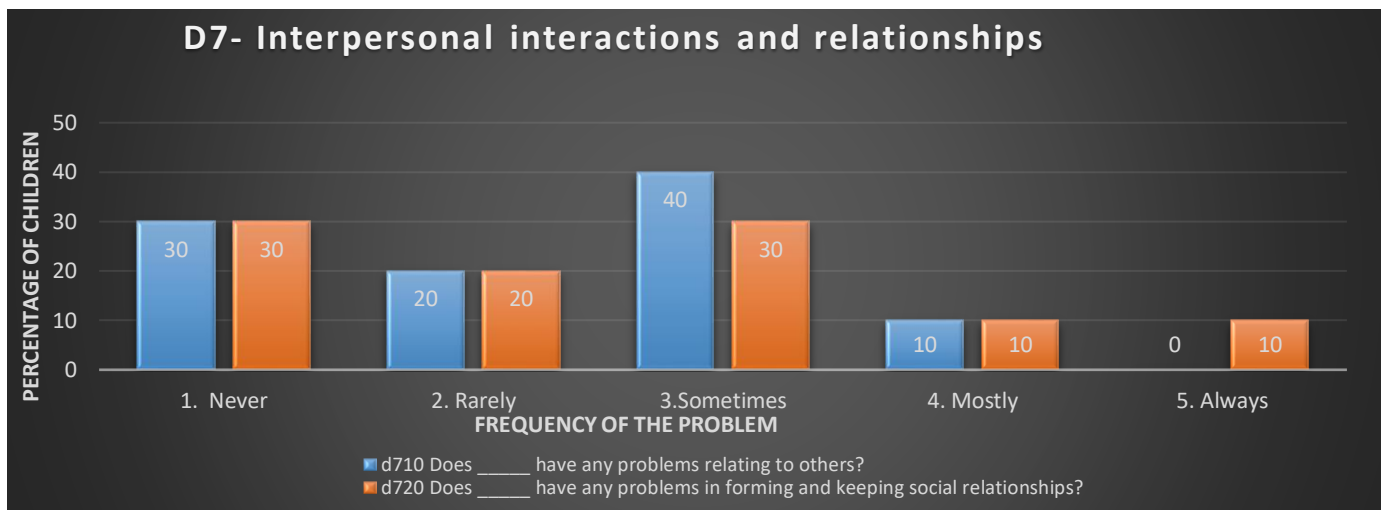
**Domain - 6 Domestic Life:** This domain had only one question which investigated the difficulties faced by children in participating in household activities.



**Graph 4: Percentage of children having problems in D6 Domain – Domestic Life.**

As seen from the graph 4, 25% of the children reported to have problems in participating in household activities most of the time. 10% had it sometimes, 15% faced difficulties rarely and remaining 50% of the children did not face any difficulty in participating in household activities.

**Domain 7: Interpersonal interactions and relationships:** This domain included two questions. Both the questions investigated the children’s ability to form and maintain interpersonal relationships.

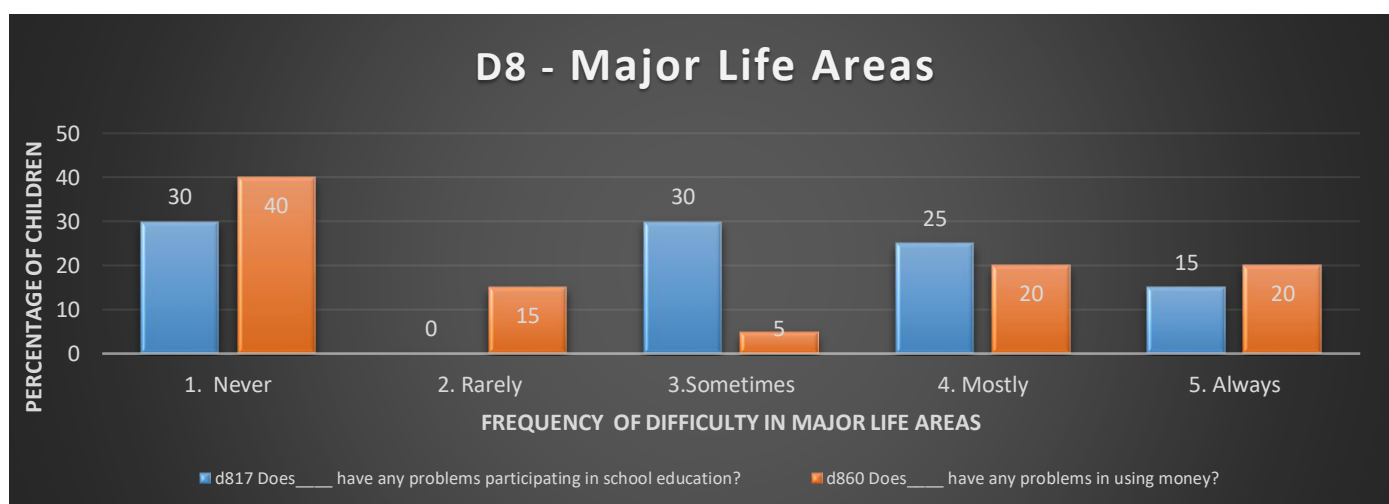


**Graph 5: Percentage of children showing difficulty in D7 Domain - Interpersonal interactions and relationships**

As seen from the graph, 40% of the children were reported to have problems relating to others (d710). 30% and 20% had the problems never and rarely respectively. In terms of forming and keeping social relations, 10% of children were reported to face this problem all the time, 10% had to face it mostly, 30% sometimes, 20% rarely and 30% of them never faced

problems in forming and maintaining social relationships.

**Domain 8: Major Life areas:** This domain had 2 questions. Two major life areas addressed here are school education and use of money

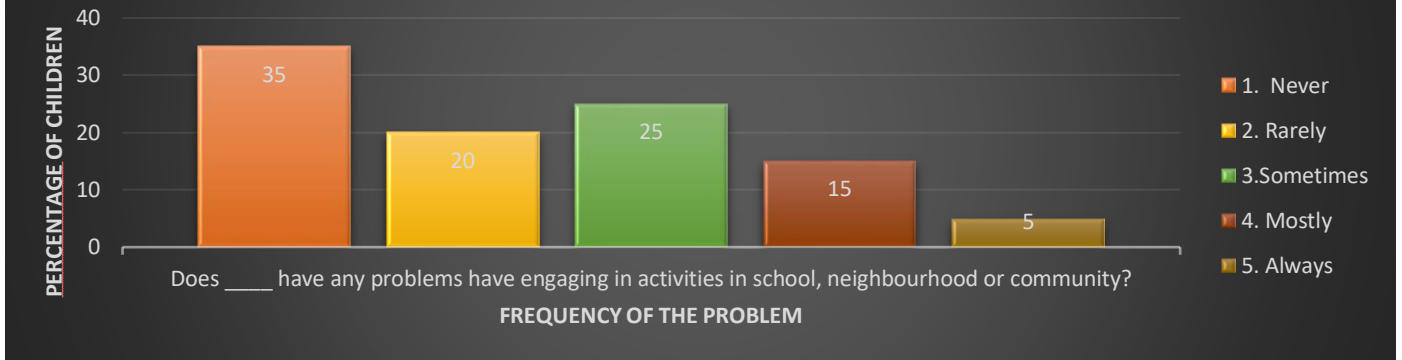


**Graph 6: Percentage of children showing difficulty in D8 domain - Major Life Areas**

As seen from the graph 6, 30% of children did not have any difficulty in participating in the school education. However, 70% did face difficulty in this area. Of which 30% had difficulty sometimes, 25% had it most of the time and 15% were reported to always have difficulty in school education. With respect to use of money, 40% did not report of any problem. 20% faced difficulty most of the time and 20% always had the problems in use of

money. Therefore, parents reported that they did not allow them to do transactions of greater amount. Rather, they gave them the exact amount to make small purchases. **Domain 9: Community, Social and Civic Life** This domain included only one item about social and civic life.

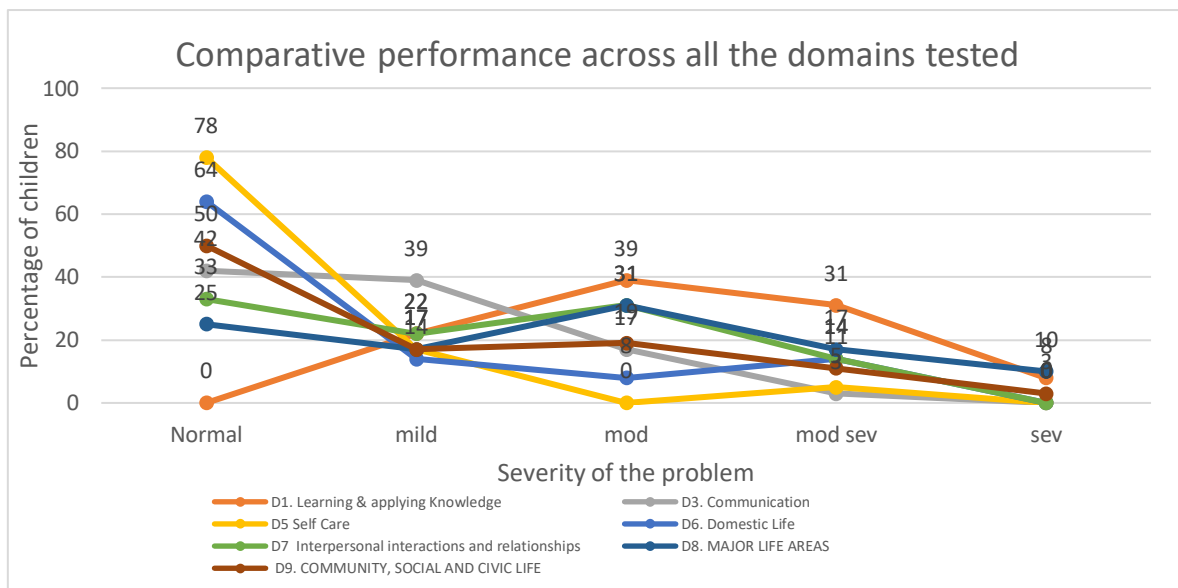
## D9 - Community, Social and Civic Life



**Graph 7: Percentage of children showing difficulty in D9 Domain - Community, Social and Civic Life**

As seen from the graph above, majority (30%) of the children **never** faced any problems in community, social and civic life. Of the remaining, 20% rarely had any difficulty, 25% had it sometimes, 15% were

reported to have the problems in community, social and civic life most of the time and only 5% of children always had the problems in this area.



**Graph 8: Percentage of children showing difficulty across all the domains tested on the checklist.**

In summary, as seen from the graph 8 below, there was no domain where children did not face any difficulty. Self-care and domestic life were the only two domains where more than 50% (78% & 64% respectively) of the children were reported to function normally. In contrast, the domain D1, learning and applying knowledge was the only area in which no child functioned in the normal range. In fact, this domain seems to pose maximum problem. For all the domains tested majority of the children had mild to moderately severe problems. Very few (less than 10%) children were reported to have severe problems across all the domains.

### **DISCUSSION:**

Activity limitations and participation restrictions due to impairment in learning and applying knowledge are highlighted as major characteristic of LD. It is well known that mental functions especially memory contribute to the problems with social and educational

functioning. As a result of the interaction between the impairments of LD and contextual factors, all children with LD experience activity limitations and participation restrictions. Therefore, it was crucial to profile the difficulties on multiple functional domains of CWLD. Assessment of multiple domains of functions is essential to determine abilities as well as potential goals and outcomes of intervention programs. Hence, the current study included 22 items under various subdomains of activity and participation components of the ICF. It addressed communication-related activity limitation and participation restrictions under various subdomains such as communication, learning and applying knowledge, interpersonal interactions and relationship, major life areas, domestic life, as well as community, social, and civic life. The results of the present study revealed that majority of CWLD, do not have much difficulty in understanding verbal or gestural



instructions, nor do they have any problems in speaking. But when it comes to reading, writing and performing calculations, they do face problems of varying severity.(d140, d145, d150 & d166) The same is reflected in their ability to use of money(d860). This finding is in accordance to studies reported in literature wherein, CWLD were reported to have math anxiety which the authors attributed to difference in the brain structures (Kucian et al 2018). Other researchers also supported presence of mathematical problems (Rubinsten & Tannock, 2010). Presence of reading and writing difficulty appears consistent across a number of research studies that have been conducted (e.g. Lesaux and colleagues (2006), Bowyer – Crane et al 2017 & Graham et al., 2020). Though these children do not have problems in speaking, surprisingly, many of them do have problems in maintaining social interpersonal relationships (d 710 & d 720). This findings is in accordance to study done by Greca (2006). This particular finding indicates the need to assess the feelings and attitudes of the children with LD which we miss out on traditional tools employed for capturing academic difficulties. In fact, 50 % of children were also reported to have difficulties in participating in own household activities (d6). Majority of the children performed satisfactorily in the domain of self-care. Though there is absence of structural involvement 15% of children were reported to have problems in avoiding self-injury. This probably points to subtle neurological involvement or atypical brain development. (Gilger & Kaplan 2001). Irrespective of severity, all 35 children were reported to have significant activity limitations and participation restrictions Thus it can be inferred from the present study, that LD cannot be viewed as presence or absence of certain characteristics. Rather, there is a spectrum of functionality ranging from no problems to rare difficulty on one end extending up to severe difficulty on the other end as demonstrated by parental report of children always having problems in some items. Raskind and Goldberg have delineated six success attributes that make a difference in being effective in life. They include self-awareness, proactivity, perseverance, goal-setting, using support systems, and emotional coping strategies. Hence, it can be inferred from the current study that the severity of learning disability is not a factor that predicts the performance of the children. In other words, even when the child faces difficulty occasionally in any domain, it can cause activity limitation and participation restriction in communication-related functional domains. Similar findings have been reported by Brown et al(1996). Results also suggest that the traditional tools are insufficient enough to profile the activity limitation and participation restriction in CWLD. Functionality assessment is crucial for the wholistic management of CWLD. Rivia & Antonietti (2010) compared the profile of a child based on ICD 10 and ICF/ICF CY and proved the utility of application of ICF. They concluded

that ICD and ICF/ICF CY are complementary to each other. Using both ICD and ICF CY can prove to be an effective strategy to enhance the quality of life of CWLD. Therefore, the current study highlights the utility of the ICF framework in documentation of activity limitations and participation restrictions and accordingly set therapy goals for effective management of CWLD.

#### **Implications of the Study:**

The current study attempted to profile the communication-related activity limitations, participation restrictions and environmental barriers in CWLD. It highlighted the implication of the ICF in profiling the overall functionality of the CWLDT irrespective of the weather they have dyslexia, dysgraphia, dyscalculia in isolation or in combination. This study has implications for making a management plan keeping in mind all the domains of ICF. Furthermore, it highlighted the need towards making not just environment outside the house but also within the household, child friendly. The study will have implications for deciding the educational status of CWLD. Since the current study focused on the overall functionality of the CWLD, it will be useful for the speech language pathologists to address the specific goals for management of CWLD on a broader perspective. Administration of ICF CY checklist can focus on documentation of the performance before and after treatment to study the efficacy of the intervention programmes. Future studies extending the same methods for CWLD having isolated dyslexia, dysgraphia or dyscalculia can be compared with children having combination of these issues.

#### **CONCLUSION:**

The present study aimed to profile performance of CWLD on various domains of ICF framework. The results highlighted unique features of CWLD as captured by the ICF framework in profiling the activity limitations and participation restrictions of CWLD. It also indicated a need for modification of the communication environment at home, at school as well as at society level for CWLD to plan towards inclusion. Thus, the interactive ICF model is highly useful for profiling a multifaceted condition like LD in holistic manner. In absence of obvious structural deficits, CWLD, do not get the attention they deserve. The study has implication for facilitating quality of life in CWLD by making suitable provisions for achieving inclusion not only at household level but at societal level at large.

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