



Evaluation of children with Down's Syndrome through ICF-CJ: comparison of parents 'and therapists' vision

Avaliação de crianças com Síndrome de Down através da CIF-CJ: comparação da visão dos pais e das terapeutas

Evaluación de niños con Síndrome de Down a través de la CIF-CJ: comparación de la visión de los padres y de los terapeutas

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Abstract

Introduction: The arrival of a disabled child brings many challenges to the family members and can impact on the child's functionality. The family's view of the child does not always match both their potentialities and deficits. It is therefore important to compare the views of the child's parents and therapists. **Objective:** To compare the views of parents and therapists regarding the functionality of children with Down Syndrome (DS). **Methods:** This is a qualitative, sample-for-convenience study with three children with DS, their parents and therapists. Data collection was done through the application of the CIF-CJ with one of the responsible of the child and with the trainee therapist responsible for each case, all of whom were attended at university speech-language pathology clinic. **Results:** After analyzing the three cases, it was observed that the difference in the responses of the family and the therapists was concentrated in the children language, especially in relation to speech. It has also been observed that therapists perceive the relationship of family members with health professionals who are more fragile

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Authors' Contributions:

BFH: Study design; data collect; article outline; ABM: Study design; article outline; critical review; tutoring; APRS: Study design; article outline; critical review; tutoring.

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Received: 12/14/2018

Accepted: 09/24/2019



than their parents. The results reinforce the importance of looking at functionality in childhood clinic.

Conclusion: In the comparison of functionality in the perception of parents and therapists, the difference in perception of the children's linguistic production was highlighted.

Keywords: International Classification of Functioning, Disability and Health; Child; Parents; Health Personnel; Down Syndrome.

Resumo

Introdução: A chegada de um filho com deficiência traz muitos desafios aos familiares podendo impactar na funcionalidade da criança. A visão que a família possui da criança nem sempre condiz tanto com suas potencialidades quanto com déficits. Por isso, interessa comparar a visão dos pais e terapeutas da criança. **Objetivo:** Comparar a visão dos pais e dos terapeutas em relação à funcionalidade de crianças com Síndrome de Down (SD). **Métodos:** Trata-se de um estudo qualitativo, de amostra por conveniência, com três crianças com SD, seus pais e terapeutas. A coleta de dados se deu por meio da aplicação da CIF-CJ com um dos responsáveis da criança e com a terapeuta estagiária responsável por cada caso, todos atendidos em clínica-escola de Fonoaudiologia. **Resultados:** Após análise dos três casos observou-se que a diferença nas respostas entre familiares e terapeutas esteve concentrada na percepção da linguagem das crianças, sobretudo em relação à fala. Também se observou que os terapeutas percebem a relação dos familiares com os profissionais de saúde mais frágeis do que os pais. Os resultados reforçam a importância sobre um olhar sobre a funcionalidade na clínica da infância. **Conclusão:** Na comparação da funcionalidade na percepção de pais e terapeutas, destacou-se a diferença na percepção da produção linguística das crianças.

Palavras-chave: Classificação internacional de funcionalidade, incapacidade e saúde; Criança; Pais; Profissional da saúde; Síndrome de Down.

Resumen

Introducción: La llegada de un hijo con discapacidad trae muchos desafíos a los familiares que pueden impactar en la funcionalidad del niño. La visión que la familia posee del niño no siempre condice tanto con sus potencialidades como con déficits. Por eso, interesa comparar la visión de los padres y terapeutas del niño. **Objetivo:** comparar la visión de los padres y de los terapeutas en relación a la funcionalidad de niños con Síndrome de Down (SD). **Metodos:** Se trata de un estudio cualitativo, de muestra por conveniencia, con tres niños con SD, sus padres y terapeutas. La recolección de datos se dio por medio de la aplicación de la CIF-CJ con uno de los responsables del niño y con la terapeuta pasante responsable de cada caso, todos atendidos en clínica-escuela de Fonoaudiología. **Resultados:** Después del análisis de los tres casos se observó que la diferencia en la respuesta de los familiares y de los terapeutas estuvo concentrada en la percepción del lenguaje de los niños, sobre todo en relación al habla. También se observó que los terapeutas perciben la relación de los familiares con los profesionales de salud más frágiles que los padres. Los resultados refuerzan la importancia sobre una mirada sobre la funcionalidad en la clínica de la niñez. **Conclusión:** En la comparación de la funcionalidad en la percepción de padres y terapeutas, se destacó la diferencia en la percepción de la producción lingüística de los niños

Palabras clave: Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud; Niño; Padres; Personal de Salud; Síndrome de Down.

Introduction

Down Syndrome (DS) is a genetic disease caused by chromosome 21¹ trisomy, which determines specific physical characteristics, delayed neuro-psychomotor development, and often expresses muscle hypotonia, sluggish growth, thyroid disorder, neurological problems, congenital heart disease, obesity, premature aging, visual, hearing and cervical spine alterations in the subjects who have it². According to the 2010 Census of the Brazilian Institute of Geography and Statistics³, 0.9% of Brazilian population from 0 to 14 years old has some intellectual disability. In Rio Grande do Sul, place of this research, 23.84% of the population presents some type of disability.

It is known that the arrival of a child with disabilities is an unexpected reality, a complex moment that has a significant impact on family members, who are also affected by the fact. It establishes a period of family crisis, being an unpredictable space that requires spontaneous and flexible maternal and paternal behaviors to produce creative and innovative solutions⁴. The event is a starting point for innumerable daily changes in the family, social environment, and psychological issues causing frustrations and impacts on the parents⁵. The event requires parents to adapt to the new reality, however, it is known that parents often have difficulty adapting to disability, which generates a distorted view of their child's development. In this context, professionals play crucial role and must call the family to build a symbolic mark, not only facing a pathology, but with a global look at their child, as a psychic, biological, cognitive and social being⁶. In this matter, therapy must be able to re-signify the disability and re-idealize the child⁴. If re-idealization does not occur, there may be important effects on family organization that may be glimpsed in daily life. The International Classification of Functioning, Disability and Health (ICF) is believed to identify some of the effects.

Considering the relevance of the contexts where the subjects are immersed in, the World Health Organization proposed using the ICF that provides a complete view to the subject in a biopsychosocial approach. It provides a standardized language for health description and establishes a scientific basis for studying health determinants and their associated conditions. The ICF - Children and Youth Version (ICF-CY)⁷ has been created due to

the need and diversity of disabilities in childhood regarding its intensity and impact promoted all over the period of child development. It is essential to elucidate the potentials and limitations of child development in children with DS considering them as subjects with individualities, inserted in various contexts that may facilitate or create barriers to their full development. Yet, parents and professionals sometimes have different views of child development. Thus, the present research aims to compare views of parents and therapists regarding the functionality of children with DS.

Method

It is a qualitative, sample-for-convenience study. The inclusion criteria were children with DS under therapeutic follow-up for at least six months, and parents and children accepting to participate in the study. The exclusion criteria were children with associated pathologies, such as Autistic Spectrum Disorder and non-progressive motor encephalopathy. Participating children receive speech therapy at a clinical school of the Federal University of Santa Maria in the city of Santa Maria in the state Rio Grande do Sul, Brazil. It's responsible and the intern therapists of the Speech Pathology course were contacted personally by the researcher in order to explain the study. After family and intern therapists had accepted attending to the study an interview was scheduled at a concurrent time with the care child in the school clinic to reduce the wastage of attending to the research. All participants signed the Informed Consent Form and the researcher signed the confidentiality agreement. The project complies with the ethical precepts contemplated in Resolution n° 510/2016 of the National Health Council⁷, which regulates researches involving human beings and is part of the project entitled "Child Development and its relationship with parental adaptation to the disability of child: association analysis with sociodemographic aspects, and clinical and educational opportunities" approved under CAAE number 02235218.9.0000.5346. Data were collected through a questionnaire with family identification, the application of the ICF-CY with one of the child's guardians, and the intern therapist responsible for the case. The researcher selected ICF-CY domains specifically for children with DS, focusing on children's occupational performance, language, social participation, and access to health

services. Then, the researcher built a questionnaire of guiding questions to select the qualifiers. The interview was recorded in audio, and afterwards the qualifiers were selected. ICF-CY components are represented by letters: Body Functions (b), Body Structures (s), Activities and Participation (d), Environmental and Personal Factors (e). In classification, the letters for each component are followed by a numeric code according to the category they belong to⁸. The ICF-CY domain qualifiers pointed out the presence and severity of a problem in functionality at the body, person, or social levels ranging from level 0 (zero) to 4 (four), 8 (eight), and 9 (nine). Level 0 corresponds to no problem or difficulty, level 1 represents mild difficulty, level 2 moderate difficulty, level 3 severe difficulty, and level 4 total or complete difficulty. Level 8 indicates unspecified degree of disability, and level 9 the non-applicable domain⁸. Regarding Environmental Factors (e), the domains by which they are formed may be considered as facilitators, due to its positive impact on the participation and functionality of an individual (+ symbol is used) or barriers if it presents a negative impact (using the - symbol). Thus, a given environmental factor may be considered as no obstacle (-0) to total obstacle (-4), or (+ 0) from no facilitator to full facilitator (+4)⁸.

Results

The study included three children with DS, named A., B., C., their families, and the intern therapists of the Speech Therapy course.

Context of Cases

A. is a four-year-old boy and his family is composed of father, mother and sister, with respective ages of 49, 44, 16. His father is a military police officer, his mother is a nurse, and his sister, a student. He goes to a part-time school where he is supervised by the intern speech therapist and attends to equine and music therapy. All activities take place weekly. A. presents excessive feeding difficulty with respect to food textures. From the occupational therapeutic evaluation, A. presents sensory alterations with symptoms of significant

oral sensitivity, so he was referred to a private clinic supervised by an occupational therapist. Parents organize themselves to intercalate the childcare. During consultations, the mother communicates more easily with A. than the father, but both are overly directive.

Child B. is a six-year-old girl and has attended to therapy since she was two years old in an early intervention project in the same service. Her family consists of father, mother and brother, with respective ages of 44, 38 and 20. Her father works in commerce, her mother is a teacher in a public high school, and her brother is a student. B. goes to a part-time school. However, the speech and occupational therapy occurs in another educational institution. Parents of B. are experiencing relationship difficulties. The mother points out the father's difficulty in exercising his paternal functions, such as settling limits to his daughter. The mother has difficulty to realize the child's limitations and emphasizes learning in reading and writing. B. has been getting along well with her father, which eventually intensifies the mother's distress. The speech therapist seeks to make B. discover the interest in writing and narrating through enjoyable book experiences and has debated with her mother about the path of B.'s writing acquisition.

Child C. is a five-year-old girl. Her family consists of mother and brother, with respective ages of 35 and 9. She started intervention at the age of three, and her mother was accompanied by a psychology intern in parallel with C.'s first visits. The father does not participate in the care of his daughter, being responsible only for the alimony. The mother has mental illness, does not work, and receives permanent financial benefit (a government aid) to be able to take care of her child. She is responsible for childcare alone and demonstrates exhaustion. C. goes to a part-time school and is supervised by the speech therapy internship at the school clinic, and the occupational therapy at the Association of Parents and Friends of the Disabled (APAE) in the city where she lives.

Answers to the ICF-CY

In A. and C. cases, the mothers answered the questionnaire, and in B. case the father.

Table 1. Distribution of qualifiers of domains belonging to Body Function component based on interviews with family members and therapists.

Domains	A		B		C	
	P	T	P	T	P	T
b134 Sleeping Functions	1	0	3	2	0	0
b210 Vision Functions	0	0	0	0	0	0
b230 Hearing Functions	0	0	0	0	0	0

Caption: (F) family; (T) therapists; (0) absence of difficulty; (1) mild difficulty; (2) moderate difficulty; (3) severe difficulty; (4) complete difficulty.

Children do not present biological limitations regarding vision and hearing functions, which was verified through objective examinations. However, families of A. and B. present sleeping difficulty. It is

known that therapists get data from the declaration of families, who consider the problem with greater magnitude than therapists.

Table 2. Distribution of qualifiers of domains belonging to Activities and Participation component based on interviews with family members and therapists.

Domains	A		B		C	
	P	T	P	T	P	T
d310 Communication-reception of verbal messages	1	2	1	2	1	1
d315 Communication-reception of non-verbal messages	0	0	0	0	0	0
d330 Speaking	1	2	2	2	2	3
d430 Lifting and Carrying Objects	0	0	0	0	0	0
d440 Fine use of hands	0	0	0	0	0	0
d450 Walking	0	0	0	0	0	0
d510 Washing up	3	3	3	3	4	4
d520 Body Care (brushing teeth, etc.)	2	2	3	3	4	4
d530 Care related to excretion processes	2	2	3	3	3	3
d540 Dressing up	2	2	3	3	4	4
d550 Eating	4	4	1	1	1	0
d560 Drinking	1	1	0	0	0	0
d710 Basic Interpersonal Interactions	0	0	0	0	0	0
d760 Family Relationships	0	0	0	2	0	1
d730 Relationship with strangers	0	0	2	1	2	0
d820 Schooling	0	0	2	2	0	0
d880 Involvement in games and play	0	0	0	0	0	2
d920 Recreation and Leisure	0	0	1	1	1	1

Caption: (F) family; (T) therapists; (0) absence of difficulty; (1) mild difficulty; (2) moderate difficulty; (3) severe difficulty; (4) complete difficulty.



Regarding the interpersonal interactions and communication of non-verbal messages domain, children understand the literal and implicit meanings of messages transmitted non-verbally, interacting satisfactorily with other subjects. However, verbal communication is identified as difficulty, in A.'s case. The boy presents excessively limited spoken language, preferring body gestures. We assume that sensory changes and oral sensitivity are

corroborating to the delay in speech development. In B. and C. cases, children express themselves easily; however, adults present difficulty to understand the speech of the children, especially the intern therapists. During the interviews, it was seen that parents tend to perform daily life activities for their children. Children end up being passive and demanding longer time to gain their independence.

Table 3. Distribution of qualifiers of domains belonging to Environmental Factor component based on interviews with family members and therapists.

Domains	A		B		C	
	P	T	P	T	P	T
e410 Individual Attitudes of Immediate Family Members	+3	+3	+3	+1	+3	+2
e415 Individual Attitudes of Extended Family Members	0	0	+1	0	+2	+1
e425 Individual Attitudes of acquaintances, peers, colleagues, neighbors, and community members	0	0	0	0	0	0
e450 Individual Attitudes of health professionals	+2	+2	+2	+1	+2	+1
e455 Individual Attitudes of other professionals	+2	+2	-2	-2	+2	+2
e580 Health services, systems and policies	+2	+2	+2	+2	+1	+1

Caption: (F) family; (T) therapist; (0) absence of barrier/facilitator; (1) mild facilitator; (2) moderate facilitator; (3) considerable facilitator; (4) complete facilitator; (-1) mild barrier; (-2) moderate barrier.

B. has presented learning difficulty at school. However, according to school material review and parental reports, the school has performed inadequate teaching methods for the child's age. The intern therapist responsible for the case reported that she has been seeking to contact the school, but the institution professionals do not show interest in holding a meeting to discuss the case. Another relevant aspect is the difficulty of B.'s mother in understanding the stages of her daughter's development, seeking to focus on schematic and directive learning methods. The fact has made B. unwilling to written language, causing dialogue difficulties between her mother and the professionals who serve her daughter. Regarding individual attitudes of other professionals, in A.'s case the answers refer to professionals who perform equine and music therapy. In B.'s and C.'s cases, answers refer to school professionals.

All families have easy access to health services. A. through the State Welfare Institute (Instituto de Previdência do Estado-IPE), B. accesses the private health system, and C. is accompanied by the Unified Health System (Sistema Único de Saúde-SUS).

Discussion

The present research shows that cases A. and B. report difficulties in sleeping functions, mainly by families, who experience these difficulties daily. However, the family members do not verbalize how significant the problem is to therapists. Having good sleep habits influences the functioning of the body, strengthening cognitive performance, improving logical thinking, learning, memorization, attention and creativity, as sleeping repairs the body and the brain⁹. Therapists are unaware of A.'s and B.'s sleeping difficulties, due to parents misunderstanding about the therapist functions, since it is a common question in speech therapy and occupational therapy.

Gross motor skills were not referred to as difficulty in this research. However, according to families and therapists, the area of self-care stood out as a significant difficulty in children with DS. It occurred once that families performed the ADLs for the child. According to Mancini et al.¹⁰, families of children with disabilities tend to perform a greater number of activities for the child, thinking of mitigating their efforts. It is essential that health



professionals working with DS children reinforce ADLs in their therapeutic projects to make children participate and develop the fullness of their functional capacity¹¹. Corroborating the findings of the study, Martins et al.¹² evaluated and compared the functional and self-care skills of children aged five to eight years old through the *Pediatric Evaluation of Disability Inventory* (PEDI). Twenty children with typical development and 17 children with DS participated in the study. Children with DS attended to an interdisciplinary therapeutic workshop with professionals of speech therapy, occupational therapy, and physiotherapy. The authors identified limitations in functional abilities in individuals with DS when compared to the typical standard group. The limitations manifested significantly in the area of self-care, however, no statistical difference between the groups were presented in the areas of mobility and social functions, despite having a more limited repertoire of skills. It is known that the subjectivity and uniqueness of each subject has significant influence on daily life. Children, as well as adults, establish their daily lives based on their occupations, such as playing, sleeping, leisure, study, and health care. The occupations differ for each subject in relation to time required and companies. The occupations, the way the child processes, the environment in which it is inserted, the relationships established with adults and other children allow skills to expand and shape the personality of the child, the way of seeing the world, wills and consequently their development¹³. Regarding the daily lives of children in the research, A. attends to two types of therapy, equine and music therapy, demonstrating a relevant daily investment in activities to favor his development. The question is to what extent these activities are not being directed by family members in a kind of “normalization” of his development favoring the eating, sleeping, and language symptoms. It is evident the family contradiction and the difficulties of re-idealization⁴ in A.’s case, mainly in his father’s difficulty to address him statements.

In B.’s case, difficulties in re-idealization are evident in her mother’s excessive search for literacy. Although therapists warn that B. still has a way of discovering writing through literacy activities, the mother insists on a pedagogical method that speeds up writing acquisition so that the girl does not lag behind other children. The conflict between the couple arises because while the mother

strongly focuses in the acquisition of competences, the father protects B., infantilizing her. The conflict negatively impacts family routine, affecting B.’s daily life so that she presents resistance in reading and writing. Therefore, everyday experiences in trying to provide adequate support for B.’s learning are not being adapted to B.’s actual demands, resulting in difficulties that may impact her way of facing the world. The children with DS in the research showed ease in nonverbal communication and interpersonal interactions. However, speech was considered as one of the great difficulties. The responses of therapists and parents sometimes differed, due to the parents’ continued coexistence with the children, and eventually realizing the way the child expresses herself. The literature presents numerous works pointing out language difficulties in children with DS, delay in the initial acquisition process, as well as the ability to speak. They emphasize how significant is the early intervention to minimize the initial delay, to offer opportunities to expand the linguistic repertoire, and minimize the neurological effects on the intellectual and language deficit, studying the family environment in the communication possibilities¹⁴ of the child. B. and C. present greater possibilities of speech production than A. They are older than A. and received early intervention. In children relationship with strangers, the mother and the therapist identified that B. presented relationship difficulty. She cannot understand when to be afraid or not before unknown people. In C.’s case, only the mother identified the same difficulty, once the therapist has contact with the child only in the school clinic where most people have known each other for a long time.

Families of B. and C. do not perform leisure activities, and as well as therapists, they identify it as not significant and crucial to their well-being. Leisure activities are taken as secondary factor in priorities of both. The fact may be associated with family difficulties observed in marital relationship of B.’s parents, and in the stress reported by C.’s mother. Gomes¹⁵ reinforces that leisure is a necessity of human being. It comprises a cultural dimension present in people daily lives at all time, places, and contexts, and constructed through the interaction of the subject with lived experience. Leisure is a field of social practices that allow the subjects to elaborate, learn and express themselves toward higher quality of life. A study evaluated the relationship between self-efficacy, emotional



adjustment, and quality of life in 209 adults, aged 18 to 55, randomly selected in the city of Lisbon. It found that individuals who practice sports and have some kind of leisure have higher indices of quality of life, while subjects with no leisure present higher indices of depression¹⁶. Regarding school education, only B.'s family and therapist reported as difficulty, due to the resistance of her teachers to adapt to the limitations of the child. Teachers use inappropriate materials for the girl's age generating frustration for B. and her family. Currently, educational public policies support the inclusion of students with disabilities in regular school classrooms based on the democratic perspective of education¹⁷. Thus, discussions arise about school institutions, pedagogical practices and curricula that cover the heterogeneity of students, and training teachers to intervene with students who present disabilities¹⁸. A suitable curriculum vision for the class does not refer to the construction of an exclusive curriculum for the student with disabilities, but rather to develop it from the emerging specificities. Curriculum flexibility is essential to meet the particularities of all students in the teaching and learning processes¹⁹. According to Rondal²⁰, the literacy levels that children with DS may achieve in reading and writing are variable. There are no related parameters for learning to be distinct from children with typical developing. However, children with DS tend to require longer time to acquire skills and require the use of specific strategies.

In this research, family relationships were identified as presenting difficulties only by therapists, just as the attitudes of immediate family members were scored lower in B.'s and C.'s cases by therapists. The fact addresses us to reflect on the family difficulty to identify disturbances in their relationship. In B.'s case, parents are in a marital crisis and while talking to the researcher they presented emphatic discussions about childcare, accusing and charging each other. In C.'s case, the mother is exhausted in caring for the child, and requests to wait in the waiting room while her daughter is attended at the school clinic, and at other times participates in the session. In A.'s case, parents organize themselves by shifting responsibility for childcare. The data evoke to what Silva and Dessen²¹ highlight about the importance of investigating the processes related to the dynamic functioning of families with DS children, either in research or in the clinic. The family establishes the child's first

relationships as a mediator of interactions in every environment. Having a child with developmental difficulties is known to be a major challenge to affective, emotional, and social functioning of parents, threatening their mental health and well-being. The child plays a relevant role in the development of individuals who are parents. Just as a child needs parents to develop, parents need to be in the developmental process to be the appropriate caregiver⁴. Silva and Dessen²² reported the interaction standards between five DS children aged two to four years old and their parents. Afterwards, they compared them to the interaction standards of five children with typical development, and their parents regarding the quality of interactions. According to the results, the interaction presents significant positive percentages between parents and children with DS (80 to 82%), however, lack of synchrony and the presence of conflicts when compared to the group with typical development. The same was identified in the families of B. and C. in this research. Regarding attitudes of the extended family, C.'s mother reported receiving great help from her sisters. According to the therapist, the care received is aimed at performing housework and basic care for children; however, she does not receive emotional support. In B.'s case, parents reported receiving extended family support to the research. They declared that help comes from family members living in another city and have never mentioned the fact to the therapist. A.'s case does not receive support from other family members; however, they are more organized. Regarding support of others in the community, no family reported receiving it. According to Franco²³, receiving support is essential for the family to get organized, either from interfamily or social networks, and the professionals involved contribute to strengthen bonds sooner. Regarding the relationship with health professionals, B.'s and C.'s parents pointed to an easier relationship than the therapists. During the interviews, B.'s mother presented difficulty investing in the relationship with her daughter, as she cannot understand the therapist guidelines and discourse. C.'s mother presented distinct discourses in the research answers, and the information given to the therapist, especially in the playing domain. C.'s mother declared she rarely plays with her daughter, but to the therapist she said that they often play together. It is believed that during the session the mother realized that playing is a facilitating

strategy for the development of her daughter, and therefore sought to respond as expected by the therapist. However, her fatigue and mental illness disables her to participate more actively, as seen along a few days of care. According to Lima et al.²⁴, daily relationship and interactions between professionals and family require empathy. Moreover, it is essential to place themselves as actors and subjects, backed by dialogue and bonds built according to health, society, and world view. According to Maciel²⁵, health professionals who assist children with DS must consider the situation in which the child and family find themselves. And thereby, plan their actions aiming to provide information, encouragement and support to the family, directing the ways for the child caregivers feel safe to face daily care challenges. Yet, therapists support parents in the positive assessment of the situation so that they may adapt to the new context.

Therapists may use ICF-CY to access daily data in order to better identify the demands of each case. The ICF-CY is a significant tool for professionals and has been widely used in child assessments to children with cerebral palsy²⁶, hearing impairment²⁷, Duchene dystrophy²⁸, among other pathologies. The tool may be used in other ways, as well. Björck-Åkesson et al.²⁹ mapped an early intervention program with the aim of establishing a unified language among the different team professionals. Hwang³⁰ used the ICF-CY to evaluate and monitor children from birth to two years old, and one of the results was how relevant is the family context on the development of the child.

Conclusion

The results regarding the differences between the responses of family members and therapists cover questions about children's communication, specifically in speech delay. When it comes to relationships, immediate family attitudes, extended family attitudes, and relationship with health professionals, therapists consider them weaker than parents.

It was clear that families experience difficulties regarding their relationships and the understanding of their children limitations. Therefore, it is essential that professionals look beyond child development, taking care of the whole family. The healthy relationship is based in mutual trust so that the family feels welcomed to share its anxieties and doubts

throughout the treatment process. The research findings showed similarities in the discourse of family members and therapists concerning the ease of children in carrying out gross motor activities, the access to health services, individual attitudes of other professionals. Parents and therapists reported difficulties in ADLs and leisure and reinforced the importance of following the process of school inclusion of children. Health and education professionals need open dialogue to build an appropriate environment for all students.

The ICF-CY is presented as tool that provides significant help in the assessment, monitoring and intervention in childhood area. It allows a wide view on health, shifting the focus from the child and/or family limitations to the study on possible intervention strategies beyond the clinic. However, the lack of instructions on how to apply them makes classification of qualifiers difficult. It is suggested to expand researches on the relationship of the studied variables so that they may be better understood and discussed, in order to provide a healthy development for children with DS.

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