RIGHTS OF THE CHILD WITH FUNCTIONAL DIVERSITY

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ABSTRACT

Objective: To describe relevant aspects of the rights of children with functional diversity. Methodology: This is a descriptive, exploratory, cross-sectional study with a quantitative approach and the purpose of evaluating the rights of 95 children with functional diversity in an outpatient clinic of a public health institution. The research was approved by the UPE Research Ethics Committee opinion number: 2.753.756 and CAAE 67017117.8.0000.5192, part of the information came from those responsible, after the application of TALE/TCLE in compliance with resolution CNS 466/12. The data were descriptively analyzed through absolute and percentage frequencies. To evaluate the association between two categorical variables, Pearson's Chi-square test or Fisher's exact test were used when the condition for using the Chi-square test was not verified. Results: It was seen that most children were having access to health, education, leisure and quality housing, however there are still children with different realities facing difficulties to guarantee these rights, especially low-income children. Conclusion: Although children are having rights, health care had a low percentage of children being monitored at the Basic Health Unit through childcare.

Keywords: Intellectual Disability. Rights of the Child. Child.

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INTRODUCTION

Functional diversity is the term used to designate people with disabilities, regardless of type or degree, in a non-pejorative way. In the first civilizations, such people were despised and excluded from social life. Nowadays, the situation has improved and inclusion is conquering its space, however there are still barriers to be deconstructed (PEREIRA, 2009).

To address functional diversity, however, it is necessary to first understand some diagnoses that are corresponding. Autism Spectrum Disorder (ASD) is a diagnosis that encompasses autistic disorder, Asperger's disorder, pervasive developmental disorders, among others. The incidence of ASD is 1 in 68 children and its diagnosis is clinical by observing behavioral symptoms (REIS et al., 2019). Attention Deficit Hyperactivity Disorder (ADHD) can coexist with ASD or it can come as an isolated diagnosis. The child with this disorder may be predominantly inattentive or impulsive or have both characteristics in combination (HORA et al., 2015)

Down Syndrome, in turn, is a genetic alteration in the chromosomes and causes mental retardation, typical physical characteristics, comorbidities, etc. The proportion is 1 in every 1000 live births. Intellectual development delay can be classified as mild, moderate or severe (COELHO, 2016).

Among many shortcomings, these examples were chosen to contextualize their needs. The development of children with functional diversity does not depend only on the degree to which they are intellectually affected, because in a more systemic view, several factors are considered affecting their development, the main one being the family environment (FRANCO, 2016). In addition, it is known that the first years of a child's life constitute a critical period in their cognitive development, and the role that the family plays in this period is of fundamental importance, especially to defend their rights (Bhutta ZA et al., 2013).

The well-being of children is also related to the place where they live and the quality of play is fundamentally shaped by the environment where it takes place (LIMA, 2015). However, public policies need to be active, as this play and children's learning, in addition to their closer relationships and social interactions, depend on the quality of the spaces and places they inhabit (AMADO, 2017).

Entering, then, the field of the rights of people with functional diversity, the current educational policy encourages school practices that promote inclusion. For this new direction, the 1988 constitution established a path with enrollment for children with disorders or syndromes in regular classes, along with neurotypical students, and a support

of specialized educational care to complement or supplement schooling (KASSAR, 2011).

Children have the right to education, aiming at their full development, preparation for the exercise of citizenship and qualification for work, ensuring them equal conditions for access and permanence in school; the right to be respected by their educators; to contest evaluation criteria, being able to appeal to higher school instances; the right to organize and participate in student organizations; access to free public schools close to their residence; according to the Statute of the Child and Adolescent of 1990.

Children are also entitled to receive from the Unified Health System a preventive service through the necessary vaccination to avoid diseases (LAW N° 8.069, OF JUNE 13, 1990), for greater validity to the preservation of health. It is essential that children are immunized, according to the vaccination schedule recommended by the Ministry of Health, in order to avoid the occurrence of vaccine-preventable diseases (MINISTRY OF HEALTH, 2014).

In public health, screening means identifying, in an asymptomatic population, individuals who are at risk of developing a certain disease. Based on this, in 2001, the Ministry of Health created the National Neonatal Screening Program (PNTN), aiming to guarantee all newborns universal access to such identification, additional investigation, immediate preventive or therapeutic action (BOTLER et al., 2010).

The United Nations Committee on Economic, Social and Cultural Rights states that it is an essential obligation of the State to guarantee society access to a minimum, nutritionally adequate and safe essential food, and to guarantee access to housing, sanitary conditions, and drinking water, thus providing minimum health conditions. The guarantee of the child's right to health refers to the need for comprehensiveness in care and the empowerment of caregivers and families, through the construction of knowledge and strengthening of competencies and skills related to care and attitudes of defense, in which the professional plays the role of facilitator and mediator, seeking to promote and guarantee the right to health (SANTOS, et al, 2015).

Thus, the importance of a multidisciplinary team to act in the assistance of this development is emphasized in order to guarantee the social rights of these children. Thus, together with the service, the family can offer the basic conditions correctly with special support from nursing, acting decisively to connect with other services and meet these needs. Health professionals need to broaden the concept of their practice to truly comprehensive care, in the understanding that health is an expanded concept. As a result, the health and human team of the service is questioned about the preparation to care for these children and act in the conditions of these families (TAVARES et al., 2021).

Historically, the population with any type of functional disability, especially intellectual disability, has had its rights denied by society. If we take into account the past, much has been done to mitigate inequalities, but it is a fact that there is still much to be done (PEREIRA, 2009). As seen in the paragraphs above, the right to comprehensive health, quality housing, education, among others, are recorded in the laws. However, it is important to question whether this right is applied in practice.

To this end, the objective of this article was to describe relevant aspects of the rights of children with functional diversity by characterizing the sociodemographic profile of their families, the profile of health care that these children receive, the analysis of their dietary profile and their access to education, in addition to measuring the attainment of leisure and family assistance.

METHODOLOGY

This is a descriptive study by establishing the relationship between variables, exploratory involving interviews with people, cross-sectional with a quantitative approach. Which aimed to evaluate the rights of children with functional diversity in an outpatient clinic specialized in child health, of a public health institution. This descriptive research aimed to contextualize various situations and relationships that occur in the lives of children with functional diversity, according to information provided by the mother or companion, in addition to the descriptions that evidenced the relationships between the functional diversity of children and their clinical, demographic and sociocultural conditions. It was characterized by the use of the quantitative approach to the collection of information for the use of statistical techniques, being complemented by the descriptive study seeking to translate into numbers the quantification of the data and information related to the study.

The study was carried out at the Pediatrics Outpatient Clinic of the Amaury de Medeiros Integrated University Health Center – CISAM, belonging to the University of Pernambuco (UPE). This institution was chosen because it offers availability and access to carry out the research. Mainly because it is a specialized outpatient care service.

The population of this study consisted of 95 children up to 10 years of age, with a diagnosis of functional diversity, who were treated at the institution. Part of the information came from those responsible.

The data were descriptively analyzed through absolute and percentage frequencies. To evaluate the association between two categorical variables, Pearson's Chi-square test or Fisher's exact test were used when the condition for using the Chi-square test was not verified. The margin of error used in the decision of the statistical tests was 5%. The data

were entered into the Excel 2010 spreadsheet and the program used to obtain the statistical calculations was the IMB SPSS in version 23.

Data collection was carried out through interviews, guided by an instrument of specific elaboration to respond to the objectives of the research, in the outpatient clinic, at the time of idleness, where the mothers wait for their health care.

The research met the recommendations of Resolution 466/12 of the National Health Council/Ministry of Health – CNS/MS, which deals with research carried out with human beings, in order to guarantee their anonymity, privacy, confidentiality, the right to withdraw at any time without any penalty, as well as to ensure the absence of burdens related to their participation, with the use of TALE and ICF. Its realization was approved by the Ethics and Research Committee with human beings of the UPE opinion number: 2.753.756 and CAAE 67017117.8.0000.5192.

As this is a research with a face-to-face questionnaire, each family was approached in an individualized environment, avoiding possible constraints depending on the interpretation. For these, protective clarifying arguments were thought of and in the end, no eventuality occurred. As for the confidentiality and secrecy of the identity of the interviewees, they were respected. The benefit of this study was the identification of the current situation of children with rights not respected and opportunities for guidance and clarification after data collection.

RESULTS

Of the 95 children studied, the majority (72.6%) were male. Almost all (91.6%) had a confirmed diagnosis of functional diversity and of this total the most frequent diagnoses were: autism/hyperactivity (46.3%), Down syndrome (18.9%) and other diagnoses (25.3%) and most (80.0%) of the diagnoses were made by the doctor.

Regarding the economic situation, the income range of 1 to 2 minimum wages was the most prevalent, with 57.9% of the group, followed by those who had an income of less than one minimum wage (33.7%) and the remaining 8.4% had an income of more than 2 to 3 minimum wages; 38.9% received the Continuous Cash Benefit (BPC) and the remaining 3.2% lived with other government aid.

Regarding housing, the majority (63.2%) lived in their own house, followed by 30.5% lived in a rented house and 6.3% lived in a rented house. The majority (96.8%) had masonry housing and the remaining 3.2% were made of wood/rammed earth; the most frequent type of floor was ceramic with 64.2%, followed by 29.5% with cement and the remaining 6.3% were made of beaten earth; The majority (63.2%) of the access to the

household was asphalt and the remaining 36.2% was dirt. A little less than half (49.5%) had 5 to 6 residents in the household, followed by 31.6% who had 7 to 11 residents and the remaining 18.9% had 2 to 4 residents. All had electricity in their homes, most had running water (94.7%), basic sanitation (88.4%) and garbage collection (86.3%).

Table 1 – Distribution of socioeconomic and clinical variables of children with functional diversity treated at the specialized pediatric outpatient clinic of CISAM, Recife-PE.

Variable	N	%
TOTAL	**95**	**100,0**
Child's age group		
Up to 4	33	34,7
> 4 a 8	44	46,3
> 8	18	18,9
Sex		
Male	69	72,6
Female	26	27,4
Confirmation of the diagnosis of functional diversity	87	91,6
Diagnostics		
Autism/hyperactivity	44	46,3
Down	18	18,9
Mental deficit	1	1,1
Other	24	25,3
Attend school	60	63,2
It has a health booklet	90	94,7
BMI Classification		
Adequate	56	58,9
Not suitable	39	41,1
Practice of physical activity	18	18,9
Vaccination updated according to age group	76	80,0
Number of professionals the child is monitored		
None	5	5,2
1 a 3	53	55,8
4 a 8	37	39
Children accompanied by a nurse	15	15,8
Children who attend USF where they live	66	69,5
Children who have had neonatal tests		
Performed	90	94,7
Didn't perform	5	5,3
Types of infections/diseases acquired during childhood		
No	40	42,1
Viral and/or bacterial	37	39
Other (congenital/allergies/surgeries)	18	18,9
	63	66,3

Use of medication (antidepressants/antipsychotics/sedatives/stimulants/ diuretics)		
Reconciles sleep well	74	77,9
Number of meals per day		
3 a 5	42	44,2
6 a 8	53	55,8
Children who received exclusive breastfeeding		
Did not breastfeed	23	24,2
Less than 4 months	41	43,2
Up to 6 months	31	32,6
Children were breastfed		
Did not breastfeed	23	24,2
Less than 4 months	27	28,4
Up to 6 months	45	47,4
Children who have had supplementation		
Didn't	19	20,0
Vitamins and/or iron	76	80,0
Children who frequent public places	92	96,8
Children who have hobbies (hobby)	90	94,7

Table 2 shows a significant association between diagnosis and time of diagnosis, and for this variable it is highlighted that: the percentage that was less than one month old was 66.7% and ranged from 2.3% to 16.0% in the other diagnoses and the percentage that was more than 2 to 4 years old was 34.1% among those who had autism/hyperactivity, it was null among those with Down syndrome and 24.0% among the other diagnoses. Regarding the professional who made the diagnosis, the majority (87.4%) was performed by a physician.

Table 2 Characterization of the children's outpatient care in terms of the professional who made the diagnosis, time of diagnosis, number of professionals who accompany and who follow up with multiprofessional stimulation according to each diagnosis of children with functional diversity attended at the specialized pediatric outpatient clinic of CISAM, Recife-PE.

	Diagnosis								
Variable	**Autism/Hyperactivity**		**Down**		**Other**		**Total Group**		**P value**
	n	%	N	%	N	%	N	%	
TOTAL	**44**	**100,0**	**18**	**100,0**	**25**	**100,0**	**87**	**100,0**	
Professional who made the diagnosis									$p^{(1)}$ = 0,390
Doctor	38	86,4	18	100,0	20	80,0	76	87,4	
Psychologist	1	2,3	-	-	1	4,0	2	2,3	
Other professional	5	11,4	-	-	4	16,0	9	10,3	

Diagnosis time									$p^{(1)}$ < 0,001 *
< 1 month	1	2,3	12	66,7	4	16,0	17	19,5	
1 to 6 months	13	29,5	3	16,7	8	32,0	24	27,6	
> 6 months to 2 years	10	22,7	3	16,7	5	20,0	18	20,7	
> 2 to 4 years	15	34,1	-	-	6	24,0	21	24,1	
> 4 years	5	11,4	-	-	2	8,0	7	8,0	
Number of professionals the child is monitored									$p^{(1)}$ = 0,286
None	1	2,3	-	-	3	12,0	4	4,6	
At	12	27,3	4	22,2	1	4,0	17	19,5	
2 a 3	15	34,1	6	33,3	11	44,0	32	36,8	
4 a 5	11	25,0	5	27,8	7	28,0	23	26,4	
6 a 8	5	11,4	3	16,7	3	12,0	11	12,6	
Frequency in the space of therapies or follow-up of multiprofessional stimulation									$p^{(2)}$ = 0,672
Yes	30	68,2	13	72,2	15	60,0	58	66,7	
No	14	31,8	5	27,8	10	40,0	29	33,3	

(*) Significant difference at the level of 5.0%
(1) By Fisher's Exact Test
(2) By Pearson's Chi-square test.

The results in Table 3 were presented in order to show the relationship between diagnosis and certain data. It was seen that the largest age group of children with Down syndrome (44.4%) was up to 2 years old, while this same age group was null among children with autism/hyperactivity. Another fact is that males were the most frequent in all diagnoses.

Table 3 – Description of the sociodemographic and clinical profiles according to the diagnosis of children with functional diversity attended at the specialized pediatric outpatient clinic of CISAM, Recife-PE.

	Diagnosis								
Variable	**Autism/Hyperactivity**		**Down**		**Other**		**Total Group**		**P value**
	n	%	n	%	n	%	N	%	
TOTAL	**44**	**100,0**	**18**	**100,0**	**25**	**100,0**	**87**	**100,0**	
Child's age range (years)									$p^{(1)}$ < 0,001*
Up to 2	-	-	8	44,4	5	20,0	13	14,9	
> 2 a 4	5	11,4	5	27,8	5	20,0	15	17,2	
> 4 a 6	13	29,5	4	22,2	3	12,0	20	23,0	
> 6 a 8	14	31,8	-	-	7	28,0	21	24,1	
> 8	12	27,3	1	5,6	5	20,0	18	20,7	

Sex									$p^{(2)}$ = 0,206
Male	36	81,8	12	66,7	16	64,0	64	73,6	
Female	8	18,2	6	33,3	9	36,0	23	26,4	
Sanitation									$p^{(1)}$ = 0,302
Yes	40	90,9	14	77,8	23	92,0	77	88,5	
No	4	9,1	4	22,2	2	8,0	10	11,5	
BMI Classification									$p^{(1)}$ = 0,108
Marked thinness	2	4,5	-	-	1	4,0	3	3,4	
Thinness	2	4,5	2	11,1	1	4,0	5	5,7	
Adequate	21	47,7	7	38,9	14	56,0	42	48,3	
Risk of overweight	2	4,5	6	33,3	1	4,0	9	10,3	
Overweight	6	13,6	-	-	3	12,0	9	10,3	
Obesity	8	18,2	3	16,7	2	8,0	13	14,9	
Severe obesity	3	6,8	-	-	3	12,0	6	6,9	
Reconciles sleep well									$p^{(2)}$ = 0,684
Yes	33	75,0	14	77,8	21	84,0	68	78,2	
No	11	25,0	4	22,2	4	16,0	19	21,8	
Going to the cinema									$p^{(2)}$ = 0,006*
Yes	21	47,7	4	22,2	3	12,0	28	32,2	
No	23	52,3	14	77,8	22	88,0	59	67,8	
The child received exclusive breastfeeding until what age?									$p^{(2)}$ = 0,336
Did not breastfeed	8	18,2	5	27,8	9	36,0	22	25,3	
Up to 6 months	13	29,5	6	33,3	9	36,0	28	32,2	
Less than 4 months	23	52,3	7	38,9	7	28,0	37	42,5	
Up to what age was the child breastfed?									$p^{(1)}$ = 0,254
Did not breastfeed	8	18,2	5	27,8	9	36,0	22	25,3	
Up to 6 months	21	47,7	8	44,4	13	52,0	42	48,3	
Less than 4 months	15	34,1	5	27,8	3	12,0	23	26,4	

(*) Significant difference at the level of 5.0%
(1) By Fisher's Exact Test
(2) By Pearson's Chi-square test.

Table 4 shows a significant association between going to school and the age group, where it is emphasized that: the percentages of those who had already gone to school ranged from 6.7% to 16.7% in the two youngest age groups up to two years and 2 to 4 years and ranged from 88.9% to 91.3% in the other three age groups.

Table 4 – Description of school attendance according to the age group of children with functional diversity attended at the specialized pediatric outpatient clinic of CISAM, Recife-PE.

	Going to school						
Child's age group	**Yes**		**No**		**Total Group**		**P value**
	n	**%**	**N**	**%**	**n**	**%**	
Up to 2	1	6,7	14	93,3	15	100,0	$p^{(1)} < 0,001$*
> 2 a 4	3	16,7	15	83,3	18	100,0	
> 4 a 6	19	90,5	2	9,5	21	100,0	
> 6 a 8	21	91,3	2	8,7	23	100,0	
> 8	16	88,9	2	11,1	18	100,0	
TOTAL	**60**	**63,2**	**35**	**36,8**	**95**	**100,0**	

(*) Significant association at the level of 5.0%
(1) By Pearson's Chi-square test.

DISCUSSION

In child health care, attention to their essential needs is essential (SANTOS, 2015). The child has the right to protection of life and health, through the implementation of public social policies that allow birth and healthy and harmonious development, in conditions worthy of existence (ESTATUTO DA CRIANÇA E DO ADOLESCENTE, 1990).

There is no health without income. Therefore, Social Security guarantees the Continuous Cash Benefit (BPC-LOAS) to citizens with long-term impediments, whether physical or intellectual, that hinder full participation in society. However, there are a series of criteria to grant such a benefit, which means that not all children with functional diversity will have this right (PINHEIRO, 2016). In the current survey, approximately 40% of the children were receiving the BPC, which enables a better quality of life for them and their families, however this survey has limits, not answering whether the 60% who were not covered by this policy are living safely.

However, it is understood that public policies are evolving in the country and have a role of great importance in territorial development, but they cannot be seen as the main agents of this development, their role is restricted to creating mechanisms that facilitate the quality of life in societies (Costa, J.B. et al, 2024) and this society needs to evolve by creating its path.

The right to school for children with functional diversity is already a reality for Brazilian civil laws, however, in addition to the presence of the child in school, it is also necessary to adapt the curriculum and provide professional training so that the laws are properly applied in practice. For this reason, inclusive education has been widely debated

since the 80s and today it seeks to ensure inclusive care that meets the special educational needs in regular schools (SIQUEIRA, 2015).

A survey carried out in Ecuador brought the importance of implementing large physical activities in schools. Research shows the benefits of exercise in children with functional diversity. The stimulation of motor skills favors motor coordination, sensory aspects and cooperates with intellectual development (RIVERA, 2019). Thus, less than 20% of the children participating in the data collection performed physical activities, that is, this act still needs to be encouraged among the disabled and neurodivergent.

Food is another extremely important factor for the development of the child in early childhood. Therefore, breastfeeding and an adequate food introduction at the correct time corroborate the growth and health of the individual. Complementary foods should be rich in iron, zinc, calcium, vitamins and folic acid and should be offered in a consistency appropriate for the age (LIMA et al., 2012).

Childhood overweight and obesity are factors that are of great concern to society in general, however this problem seems to be even more pertinent in children with functional diversity. The average BMI is usually higher among children with ASD and ADHD than in neurotypical children (KUMMER et al., 2016). In addition, the relationship between obesity and Down Syndrome has also been described by several authors. One cause that is usually pointed out is the possible clinical manifestation of hypothyroidism (CHAVES, et al., 2008). To minimize these problems, it is necessary to have an adequate diet and physical activity.

Playing is, for the child, the main physical exercise, but it is also an important way to develop the emotional and intellectual side. Therefore, it is essential that children have access to public leisure spaces, since not all of them have the financial conditions to attend private spaces. It is also essential that children have hobbies. Playfulness and lightness are typical of childhood and fundamental to stimulate independence, companionship and, in general, learning (GAMA et al., 2014).

Entering the data from the clinical field brought by the research, the data collection confirmed the information brought by the literature that ASD has a ratio of 4-5 men for every woman (REIS et al., 2019). In addition, the entire sample was mostly male.

According to data analysis, most of the children were receiving multiprofessional follow-up. It is important that they are offered treatments such as speech therapy, psychotherapy, occupational therapy, physiotherapy, psychopedagogy, etc., according to the patient's clinical needs. With the necessary multidisciplinary follow-up, few cases require drug treatment (OLIVEIRA; SANT'ANNA, 2020)

A low percentage of the children were being monitored by a nurse. These data are worrisome, since every child must be monitored at the Basic Health Unit through childcare, which aims to monitor growth and development, health education, disease prevention actions, and promote child health (MOURA et al., 2018).

FINAL CONSIDERATIONS

The research sample was satisfactory and its objectives were achieved. It was seen that most children were having access to health, education, leisure and quality housing, but there are still children with different realities facing difficulties in guaranteeing these rights, especially low-income children.

In today's society, income is the main factor to enable quality of life. Therefore, the State has the duty to cover this neediest portion of the population, minimizing inequalities. With regard to health, it is necessary not only to offer services, but also to carry out an active search by Primary Care to bring the patient the different possibilities of multidisciplinary follow-up.

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