

Inclusive education in children with Mucopolysaccharidosis IV-A: Case studies

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Abstract

Inclusive education is a model that seeks to meet the learning needs of all children and young people, with a special emphasis on those who are vulnerable to social exclusion and different disabilities, like people with Mucopolysaccharidosis IV-A. The objective of this study was to identify the educational needs in four case studies to develop a profile of educational needs of descriptive and cross-sectional scope, by applying an intelligence scale, a neuropsychological evaluation and interviews within the school and family context. As results from our study, an analysis by categories was obtained to guide the Individual Plans of Reasonable Adjustments from the framework of the Universal Design of Learning of inclusive education in Colombia. Knowledge concerning mucopolysaccharidosis was found to be scarce in the school institutions included in the study, although our findings suggest that it is an important input to monitor the processes of development and educational inclusion.

Keywords: Special needs education; Inclusive education; Educational psychology; Neuropsychology; Mucopolysaccharidosis.

Received: January 15, 2021; *Revised:* December 1, 2021; *Accepted:* December 17, 2021

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Conflict of Interest: The authors report no conflicts of interest.

1. Introduction

Education for all is understood as a fundamental human right; nations should guarantee access and permanence to the educational system for their citizens throughout the entire life cycle. The foregoing constitutes a strong call to nations to develop the necessary adjustments in education to promote access and permanence in the educational system for the diversity of people, specifically the population of people with disabilities, breaking down social, economic, political and cultural barriers. Along these lines, inclusive education appears as a bet for some countries, especially Euroamerican, derived from what is stated in the world declaration of Education for All by the United Nations Organization for UNESCO (Haggis, 1991; Whitburn & Corcoran, 2019).

According to the administrative records of the Ministry of Health and Social Protection (from the Spanish acronym MSPS), it was estimated that about 1.3 million people had a disability in Colombia as of August 2020. The Registry of Location and Characterization of People with Disabilities indicates that this corresponds to 2.6% of the Colombian population (Ministerio de Salud y Protección Social de Colombia, 2020a). In the country 315,275 people do not attend formal education due to their disability (Ministerio de Salud y Protección Social de Colombia, 2020b), a panorama in which the possibility of inclusion is more distant for people with disabilities, despite the public policies in favor of access to education (Rojas, 2020).

People with Mucopolysaccharidosis (MPS) are configured as a section of the population, which is integrated within the population with disabilities. MPS is recognized in the health system through the Law 1392 of 2010 and the Law 1438 of 2011 as being categorized as an orphan disease whose phenotypic manifestations generate various systemic difficulties (World Health Organization, 2001; El Congreso de la República de Colombia, 2010; 2011).

Due to their enzymatic nature, MPSs belongs to the group of lysosomal storage disorders caused by defects in the catabolism of glycosaminoglycans (GAGs), which are macromolecules that provide structural support to the extracellular matrix and have an important function in cellular regulation and communication processes (Lachman, Burton, Clarke, Hoffinger, Ikegawa, Jin *et al.*, 2014; Castañeda-Ibáñez & Acosta-Barreto, 2016; Erazo-Narváez, Muñoz-Vidal, Rodríguez-Vélez, & Acosta-Aragón, 2020; Van der Lee, Morton, Adams, Clarke, Eisengart, Escolar *et al.*, 2020). MPSs can be

distinguished in various types (Puentes-Tellez, Lerma-Barbosa, Garzon-Jaramillo, Suarez, Espejo-Mojica, Guevara *et al.*, 2020), which are the following: MPS I or Hurler Syndrome (Hurler, Hurler-Scheie and Scheie), MPS II or Hunter Syndrome (variants A and B), MPS III or Sanfilippo Syndrome (AD variants), MPS IV or Morquio Syndrome (variants A and B), MPS VI or Maroteaux Lamy, MPS VII or Sly Syndrome and MPS type IX or Natowicz Syndrome.

Epidemiological data concerning the disease in Colombia is scarce (Bernal & Briceño, 2006; Moreno-Giraldo, Satizábal-Soto, & Sánchez-Gomez, 2020). According to Gómez, García-Robles and Suárez-Obando (2012), MPSs have a general prevalence of 1.98 cases per 100,000 live births, with MPS IV and MPS VI being the most frequent types in the country (Pachajoa & Rodriguez, 2014). MPS type IV-A (Morquio A) is characterized by the development of defects of the osteoarticular system and of the supporting tissue due to alteration of the metabolism of keratin sulphate and chondroitin sulphate, producing the accumulation of these compounds in the body tissues, in particular in the bones, cartilage, heart and lungs (Erazo-Narváez *et al.*, 2020). In general, the alterations appear between the first and third year of life, with short stature, short trunk, pectus carinatum, kyphoscoliosis, hypermobility, instability of the cervical spine and vertebrae, similar to MPS type VI, but with differences in the coarse facies. Other features include corneal opacity, hearing loss, short neck and odontoid hypoplasia, hypermobility in the hips and hands, genu valgum (or knock-knee), and flat feet. At the neuropsychological level, low to normal cognitive functioning is preserved as well as a measure of intelligence (Castañeda-Ibáñez, Castañeda-Ibáñez, Mora Matallana, Prado Rivera, Rizo Arevalo, Cardenas Poveda *et al.*, 2017; Ibáñez Castañeda, Castañeda-Ibáñez, Mora Matallana, Prado Rivera, Rizo Arévalo, Cárdenas Poveda *et al.*, 2017; Van der Lee *et al.*, 2020).

In Colombia, the background tracking on the cognitive performance characteristics of MPS is scarce. Castañeda-Ibáñez and Acosta-Barreto (2016) first described the neuropsychological characteristics of people with MPS by carrying out a neuropsychological characterization of children, adolescents and adults from Bogotá and Cundinamarca; they continued their studies with a further publication (Castañeda-Ibáñez *et al.*, 2017) together with other reports, which were focused on interventions derived from neurorehabilitation and cognitive stimulation (Vásquez Salazar, Castañeda Soto, Flórez Duarte, & Cárdenas Poveda, 2017; Castañeda-Ibáñez, Gómez Suarez, Prado Rivera, Rizo Arévalo, Cárdenas Poveda, Beltrán Beltrán *et*

al., 2018). These studies reported that families and some of the patients manifested difficulties in their experience at school, especially concerning the transport and movement of the children between the classrooms due to the lack of ramps, lifts or spaces for wheelchairs. The placement of children using wheelchairs at the back of the classrooms, furthermore, increased their difficulty in visual attention, due to their corneal opacity. Moreover, dictations were too quick for children with MPS, considering most of them have claw hand, which raises the need to find ad hoc solutions favoring the educational experience of children and adolescents with MPS.

The panorama of inclusive education for people with rare diseases is bleaker than for people with disabilities not associated with orphan diseases, both for patients and for their families (World Health Organization & World Bank, 2011; FEDER & CREER, 2018). The advancement of knowledge concerning orphan diseases has been largely focused on the medical, diagnostic and treatment aspects, and what it implies in terms of quality of life for the patients and their families due to the wear and tear of the parents as caregivers (López-Bastida, Oliva-Moreno, Linertová, & Serrano-Aguilar, 2016). Thus, orphan diseases have not been carefully explored in the field of education despite the fact that many of the cases are diagnosed during school age and this usually has implications in their development and education process (Darretxe, Gaintza, & Monzon-Gonzalez, 2017).

Inclusive education has been formulated as a manifest State commitment in education policies and regulations with the General Education Law, the Law 115 of 1994 and the Code of Childhood and Adolescence (El Congreso de la República de Colombia, 1994; 2006; 2009; 2013) where education is indicated as a right and highlights the commitment to guarantee education for people with disabilities. The objective in this study was to identify the educational needs of children and adolescents with MPS linked to the Colombian Association of Patients with Lysosomal Deposit Disease (from the Spanish acronym ACOPEL) to elaborate a profile of educational needs that serves as a guide in the Individual Plans of Reasonable Adjustments (from the Spanish acronym PIAR) and within the framework of the Universal Learning Design (from the Spanish acronym DUA) of inclusive education.

2. Methods

The research presented here consisted in a descriptive, cross-sectional investigation with a study of multiple cases (Yin, 2017) considering the

population of our dataset was diagnosed with a rare disease and the number of patients in compliance with the criteria, as well as the information on the subject of the study, were scarce (Zucker, 2009). Thus, the findings presented here could be relevant towards the development of actions to improve the educational conditions of MPS patients.

2.1. Participants

A convenience sampling was carried out on children, linked to ACOPEL in Bogotá (Colombia), who met the following inclusion criteria: age between 5 and 16 years old, with a schooling experience and a diagnosis of MPS IV-A (considering it is one of the most frequent MPS types in the country). All the conditions were met in 4 cases (Tab. 1). Table 2 indicates the people from the family and school context who configured the case system for the collection of information and analysis.

Table 1 – Sociodemographic data of participating children

Participant	Age	Gender	Diagnostic	Level of education	School
Case 1	10	M	MPS IV-A	Second grade	Public
Case 2	9	M	MPS IV-A	Third grade	Public
Case 3	14	M	MPS IV-A	Fifth grade	Public
Case 4	12	F	MPS IV-A	Fourth grade	Private

Note: Own elaboration based on data collected from each of the participants.

Table 2 – Members of the family and school system interviewed for the case studies

Participant	Family member	School context
Case 1	Mother	Academic coordinator School counselor Group director teacher
Case 2	Mother	Inclusion support teacher Four knowledge area teachers
Case 3	Mother	Inclusion support teacher
Case 4	Mother	Interdisciplinary team of the institution

Note: Own elaboration based on data collected from each of the participants.

2.2. Instruments

The Wechsler Intelligence Scale for Children – IV (WISC-IV): it assesses intellectual abilities, it gives a measure of the Intelligence Quotient (IQ) and specific skills linked to different cognitive domains that represent general intellectual abilities, such as verbal comprehension, perceptual reasoning, working memory and processing speed (Wechsler, 2005). The scale mean ranges from 8 to 12.

The Neuropsychological Assessment Protocol: the tests were taken from the book *Neuropsicología Infantil* (Arango Lasprilla, Rivera Rivera, & Olabarrieta-Landa, 2017) to evaluate processes, such as attention, memory, language, gnosis, praxis and executive functions. The normative data and scales for the Colombian child population are, as follows: Average: Pc 50, Normal Range: Pc 25 to Pc 75, Low Range: Pc < 25 and High Range: Pc > 75, according to age.

Semi-structured interview: it was addressed to the family and professionals in the educational context, following the validation procedure by examiners. The interview consisted of two formats: 1) an in-depth interview conducted in the family context (Skinner, 2012), in which the child's schooling experience was investigated, the perception of barriers and affirmative actions in relation to the educational institution, the communication between family and school, the identification of achievements and difficulties in school performance and the perception of the child's social relationship, and 2) a group interview performed in the school context on the characteristics of the institution's vis-à-vis inclusive education as well as the history and current conditions of the children with MPS in terms of school performance, participation, social interaction and communication with the family.

2.3. Procedure

- *Phase 1:* An initial interview was carried out, in which the objective of the study and the cognitive and neuropsychological evaluation process were explained to parents and participants, with the respective signing of the written informed consent form.
- *Phase 2:* The semi-structured interview was carried out in the family context, in which information was gathered concerning the development history of the child, as well as his/her schooling history and the current conditions of the school experience. The WISC-IV

was applied to each participant and, in a second moment, the Neuropsychological Assessment Protocol was conducted to obtain the cognitive profile of each child. Scores were analyzed according to the population scales and a neuropsychological report was prepared that was delivered and distributed to both participants and parents.

- *Phase 3:* A visit to the educational context was carried out in order to disseminate the project and obtain informed written consent to participate in a group interview that would allow gaining knowledge concerning the experience of the child in the institution and the current conditions of schooling. With the information collected in the interviews in the family and school context, the discourse analysis was carried out in the categories defined for this purpose (Tab. 3).

Table 3 – *Interviews and categories of analysis*

Category	Subcategory
Special educational needs	Permanent special educational needs Transitory special educational needs
Barriers to inclusion	Barriers to access Barriers to permanence Quality barriers
Affirmative actions	Universal Learning Design Individual reasonable accommodation plan Work team to monitor cases Communication style between family and school
Conditions for learning	Strengths for learning Learning difficulties
Socio-affective development	Autonomy Relationships: peers, teachers, family members

Note: Defined categories for interview analysis based on literature review.

- *Phase 4:* Based on the results of the cognitive and neuropsychological evaluation, as well as the categorization of the interviews, a profile of educational needs was established for each case, which could help in guiding the support that the child required in his/her educational process in terms of cognitive, motor, school and socio-affective dimensions. Finally, an analysis of the commonalities was carried out in the four cases, so that the barriers to inclusive education and the care needs for reasonable adjustments were established.

2.4. Information analysis

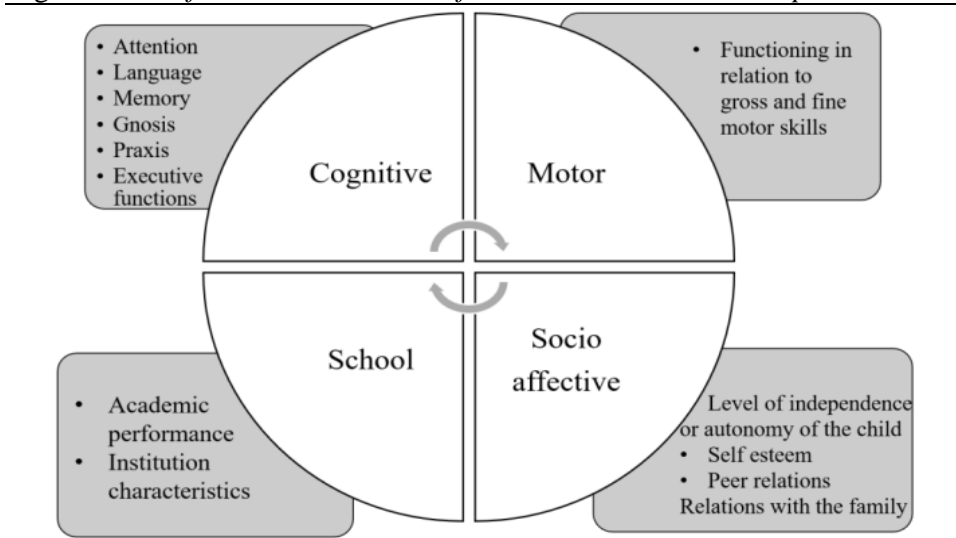
The results of the cognitive and neuropsychological evaluation tests were obtained based on what is indicated in the manuals of the tests applied, starting from the scales for the reference population, which allowed to describe the cognitive performance for each case.

The data collected in the interviews was interpreted using the discourse analysis method (Urrea, Muñoz, & Peña, 2013). The process was carried out in two phases: a deductive categorization, that started from a theoretical framework, and a further coding, which included open coding and axial coding (Tjora, 2018). The first type of coding consisted in assigning common codes to the fragments and the second in defining the categories operationally, giving rise to the subcategories.

3. Results

The results of the cognitive and neuropsychological performance were considered to prepare the profile of educational needs in each of the four cases, identifying the strengths and weaknesses.

Figure 1 – *Profile dimensions needs for the inclusive education process*



In addition, the discourse analysis of the interviews was also evaluated, which allowed to recognize the strengths and needs for each case (Fig. 1): in the cognitive dimension, constituted by language, memory and executive

functions; in the motor dimension, understood as the performance characteristics in relation to gross and fine motor skills; in the socio-affective dimension, including the child's level of independence or autonomy, self-esteem, relationships with peers and relationships with the family; and, finally, in the school dimension, which was divided into academic performance and characteristics of the institution. Guidelines were proposed for accompaniment in the inclusion process based on this analysis.

3.1. Case 1

In the WISC-IV (Tab. 4) this participant showed an expected level concerning the scales of verbal comprehension and perceptual reasoning, an extremely low score in processing speed and a limited score in the case of working memory, obtaining a final IQ that was below average. The results of the cognitive performance assessment showed a low cognitive profile for age and schooling, which could be explained by a lack of cognitive and academic stimulation, which had an impact on the development of the school skills. Despite obtaining a profile that was lower than expected, the scores concerning the skills in learning new age-specific tasks were as expected (see Tab. 5 for more details).

Table 4 – WISC-IV Score Summary - Case 1

Scale	Sum of scaled scores	Composite Score	Percentile Rank	90% Confidence Interval	Qualitative Description
Verbal Comprehension	32	102	55	96-108	Average
Perceptual Reasoning	28	96	39	90-103	Average
Working Memory	12	77	6	72-85	Borderline
Processing Speed	8	68	2	64-79	Extremely Low
Full Scale (Total IQ)	80	85	16	81-90	Low Average

Note: Sum of scales and obtainment of the IQ

Table 5 – Neuropsychological protocol - Case 1

Domains						Scores			
Attention	Memory	Language	Gnosis	Praxis	EF	Test	Raw	Percentile	
	x		x	x	x	The Rey-Osterrieth Complex Figure	Copy Memory	25 19	40 75
					x	Wisconsin Card Sorting Test- Modified (M-WCST)*	CC	3	26
							PM	15	< 5
							TM	23	20
							% PM	60%	20
x						Trail Making Test (TMT-A)	Time	60"/60"	< 5
							Errors	0	WS
x	x					Trail Making Test (TMT-B)	Time	150"/150"	< 5
							Errors	9/14	WS
x	x			x	x	Symbol Digit Modalities Test (SDMT)	Correct Score	12	< 5
	x	x				Token Test-Reduced version	Total	34.5	80
						D2 Test of Attention	Total number	161	< 5
							Total hits	47	< 5
							Total omissions	19	50
							Total commissions	4	65
							Largest	18	20
							Least	8	15
							Effectiveness	138	< 5
							Concentration	43	5
						Fluctuation rate	10	20	
						Verbal Fluency Test: Phonological Verbal Fluency Test	F Phoneme	1	10
							A Phoneme	3	15
	x	x			x		S Phoneme	0	5
							M Phoneme	1	5
							R Phoneme	3	20
							P Phoneme	5	30

	x	x			x	Verbal Fluency Test:	Animals	9	20
						Semantic Verbal Fluency Test	Fruits	7	25
		x				Peabody Picture Vocabulary Test III (PPVT-III)	Ceiling element	96	WS
							No. Errors	19	WS
							Total	77	10
	x					Test de Aprendizaje y Memoria Verbal Infantil (TAMV-I)**	Learning	25	45
							Memory delayed recall	0	< 5
							Recognition	6	< 5

Note: The Stroop Color and Word Test was not applied, the size of the stimuli was too small for the children.

Average: *Pc* 50; Normal Average: *Pc* 25 to *Pc* 75; Low Average: *Pc* < 25; High Average: *Pc* > 75; WS: Without Score.

* CC: Correct categories; PM: Perseverative Mistakes; TM: Total Mistakes; % PM: % Perseverative Mistakes

** Spanish version

As regards the information collected from the interviews in the family and school context, it was established that the most sensitive educational need for the work team was to find solutions for the child's motor disability. For this reason the school took the following measures: the institution asked the mother of the child to be present and to accompany the completion of the child's physical education activities and established the school grade, to which the child belonged, to be located on the first floor. The direction expressed concern about the possibility of maintaining the quality of the accompaniment, since the financial support required by the State was not enough and it was much more difficult to make the adaptations that the case required. Regarding the academic performance of the child, a delay was reported in carrying out activities when there was a high volume of work; the child's physical presence at school was, moreover, repeatedly interrupted by the surgical procedures he had to undergo, and, following treatment with enzyme replacement therapy, his motivation in participating to school activities markedly decreased.

On the other hand, the school reported a good communication with the family, which carried out school reinforcement at home (although not always permanently); the subject received support in the classroom for copying and reading instructions and the teachers received training in inclusive education and illness. Regarding his socio-affective development, a good relationship was reported with his peers (who sometimes tended to overprotect him) and with his teachers.

The profile needs for this case showed as strengths a development according to his age at the auditory-comprehensive level, which allowed him to follow the instructions and to have an adequate vocabulary. It also demonstrated an adequate performance in planning, organization and execution activities. At the motor level, despite the diagnosis and difficulty in mobility, the child tried to carry out the different daily chores both at home and at school, although they required reinforcement. In the socio-affective dimension, he showed basic self-care skills, the parents described him in a positive way and praised his achievements, they defined him as sociable and responsible, and his family support network was present and active in the support he required. In the school environment, the child showed a high motivation for learning, the team of teachers showed interest in the case and carried out inclusive actions; a good relationship was found between the family and the school, and the educational community in general promoted participation activities for the participant.

3.2. Case 2

Table 6 shows the results of the cognitive evaluation. The participant, in this case, presented an average score for the scales of perceptual reasoning, working memory and processing speed, with a lower score for the verbal comprehension scale, obtaining a total IQ as expected.

Table 6 – *WISC-IV Score Summary - Case 2*

Scale	Sum of scaled scores	Composite Score	Percentile Rank	90% Confidence Interval	Qualitative Description
Verbal Comprehension	21	83	13	78-90	Low Average
Perceptual Reasoning	31	102	55	95-108	Average
Working Memory	21	102	55	95-108	Average
Processing Speed	18	94	34	87-102	Average
Full Scale (Total IQ)	91	92	30	88-96	Average

Note: Sum of scales and obtainment of the IQ.

Table 7 shows the cognitive profile in terms of the neuropsychological evaluation. The participant performed with a low average cognitive functioning, which fluctuated in normality for age and schooling and was characterized by a low understanding and expression of verbal language, a decreased attentional span and a fluctuating speed of information processing. The latter could be affecting other processes, such as short-term memory. The learning skills of new tasks, as well as the handling of complex information, were preserved, which allowed the child to be on the same level as its peers. However, cognitive and extracurricular reinforcement in processes where his performance fluctuated, were considered important in this specific case.

Table 7 – *Neuropsychological protocol - Case 2*

Domains						Scores			
Attention	Memory	Language	Gnosis	Praxis	EF	Test	Raw	Percentile	
	x		x	x	x	The Rey-Osterrieth Complex Figure	Copy	24	50
							Memory	11	35
x			x		x	The Stroop Color and Word Test	Word	42	< 5
							Color	38	25
							Word/Color	16	15
							Interference	-3.95	40
					x	Wisconsin Card Sorting Test-Modified (M-WCST)*	CC	2	8
							PM	16	< 5
							TM	30	< 5
							% PM	53.3%	20
x						Trail Making Test (TMT-A)	Time	56"/60"	10
							Errors	0	WS
x	x					Trail Making Test (TMT-B)	Time	63"/150"	70
							Errors	0	WS
x	x			x	x	Symbol Digit Modalities Test (SDMT)	Correct Score	22	30
	x	x				Token Test-Reduced version	Total	33	80

							Total number	223	20
							Total hits	93	30
							Total omissions	3	65
							Total commissions	6	60
x						D2 Test of Attention	Largest	20	10
							Least	12	35
							Effectiveness	214	25
							Concentration	87	10
							Fluctuation rate	8	10
							F Phoneme	3	30
							A Phoneme	3	20
	x	x				Verbal Fluency Test:	S Phoneme	5	40
					x	Phonological Verbal Fluency Test	M Phoneme	2	10
							R Phoneme	4	30
							P Phoneme	4	25
							Animals	10	25
	x	x				Verbal Fluency Test:	Fruits	5	10
					x	Semantic Verbal Fluency Test			
							Ceiling element	108	WS
						Peabody Picture Vocabulary Test III (PPVT-III)	No. Errors	30	WS
							Total	78	15
							Learning	23	40
						Test de Aprendizaje y Memoria Verbal Infantil (TAMV-I)**	Memory delayed recall	5	10
x							Recognition	9	10

Average: *Pc* 50; Normal Average: *Pc* 25 to *Pc* 75; Low Average: *Pc* < 25; High Average: *Pc* > 75; WS: Without Score.

* CC: Correct categories; PM: Perseverative Mistakes; TM: Total Mistakes; % PM: % Perseverative Mistakes

** Spanish version

Based on the information collected in the interviews, the educational need referred to by the inclusion teacher was that the minimum use of skills in language and writing was not highlighted in relation to the age and school level in which the boy was found. Moreover, a high level of teacher discomfort was found in relation to the barriers to inclusion caused by the public policy mechanisms of the State to save money. The work team

additionally expressed that there were no guarantees for the implementation of the policy as well as the lack of specialized staff considering the high number of cases in the school; the infrastructure itself was also not equipped for inclusion (for example, the elevator was damaged). Regarding teacher training, teachers were not trained in inclusive education and were unaware of the child's illness. It should be underlined that while the family reported bullying episodes, the support team denied them. Regarding the affirmative actions, the school was provided with social service students who accompanied children with disabilities. The team agreed in their perception of the child's high level of independence and good relationship with the classmates, sharing games and activities; however, they described the participant as lazy for academic activities and slow in their execution, perhaps due to the impaired motor condition in his hands, which, notwithstanding, did not prevent him from having a good handwriting.

Finally, in terms of the delimitation of the profile, the participant showed a coherent and functional use of the language, as well as a good understanding and following of the instructions that were considered positive aspects in his cognitive dimension. The memory span was in line with chronological age, which allowed the child to learn daily, to solve problems in daily life and perform new tasks, with the ability to plan, organize and perform tasks at a visual level. At a motor level, the specific case maintained his ability to perform tasks of daily life. In terms of socio-affective development, a recognition of his independent self was demonstrated, he integrated well with both his classmates and with family members. At the school level, the mother's interest and concern for the participant's learning was recognized as well as the support of the institution with professional figures.

3.3. Case 3

Case 3 showed a borderline IQ as well as a borderline cognitive performance profile (Tab. 8 and 9) in which skills in relation to perceptual reasoning, information processing speed, and working memory were at the lower limit, compared to the performance in reading comprehension tasks, possibly due to a lack of cognitive stimulation and a decreased development in different cognitive functions. School skills presented difficulties due to two specific reasons: first, due to mental age versus chronological age, which did not allow the participant to respond at the same level as his classmates. Second, due to the clinical and physical characteristics of his

baseline diagnosis, since the participant presented high levels of fatigue and sensory fatigue. All of the above were reflected in difficulties in writing, copying or dictating, in addition to a low level of attention, as well as failures in tracking tasks and in the maintenance of both visual and auditory information.

Table 8 – *WISC-IV Score Summary - Case 3*

Scale	Sum of scaled scores	Composite Score	Percentile Rank	90% Confidence Interval	Qualitative Description
Verbal Comprehension	28	96	39	91-102	Average
Perceptual Reasoning	19	77	6	72-85	Borderline
Working Memory	10	71	3	67-80	Borderline
Processing Speed	13	80	9	75-90	Low Average
Full Scale (Total IQ)	70	78	7	75-83	Borderline

Note: Sum of scales and obtainment of the IQ.

Table 9 – *Neuropsychological protocol - Case 3*

Domains						Scores			
Attention	Memory	Language	Gnosis	Praxis	EF	Test	Raw	Percentile	
	x		x	x	x	The Rey-Osterrieth Complex Figure	Copy	27	15
							Memory	17	30
x			x		x	The Stroop Color and Word Test	Word	45	< 5
							Color	30	< 5
							Word/Color	27	15
							Interference	9	90
					x	Wisconsin Card Storing Test-Modified (M-WCST)*	CC	2	2
							PM	6	20
							TM	25	< 5
							% PM	24%	50

x					Trail Making Test (TMT-A)	Time	40"/60"	10	
						Errors	0	WS	
x	x				Trail Making Test (TMT-B)	Time	38"/150"	55	
						Errors	0	WS	
x	x			x	x	Symbol Digit Modalities Test (SDMT)	Correct Score	35	20
	x	x				Token Test-Reduced version	Total	29.5	20
							Total number	321	20
							Total hits	120	20
							Total omissions	15	55
							Total commissions	19	15
x						D2 Test of Attention	Largest	28	15
							Least	16	25
							Effectiveness	214	15
							Concentration	287	15
							Fluctuation rate	101	30
							F Phoneme	1	< 5
							A Phoneme	6	15
	x	x			x	Verbal Fluency Test:	S Phoneme	4	10
						Phonological Verbal Fluency Test	M Phoneme	5	10
							R Phoneme	5	15
							P Phoneme	4	< 5
	x	x			x	Verbal Fluency Test:	Animals	10	< 5
						Semantic Verbal Fluency Test	Fruits	5	15
							Ceiling element	132	WS
		x				Peabody Picture Vocabulary Test III (PPVT-III)	No. Errors	29	WS
							Total	103	10
							Learning	26	35
	x					Test de Aprendizaje y Memoria Verbal Infantil (TAMV-I)**	Memory delayed recall	7	10
							Recognition	8	< 5

Average: Pc 50; Normal Average: Pc 25 to Pc 75; Low Average: Pc < 25; High Average: Pc > 75; WS: Without Score.

* CC: Correct categories; PM: Perseverative Mistakes; TM: Total Mistakes; % PM: % Perseverative Mistakes

** Spanish version

The main concern of the accompaniment team about the educational needs of case 3 was the past history of the school courses in which the minimum level of learning in Language and Mathematics was not reached. He presented recurrent loss of the third degree and, at the time of the cognitive evaluation, he did not handle multiplication tables or a good execution of the drawing of lines, apparently due to the surgical procedures to which he had to undergo. In this case, the transport around the school facilities had to be carried out with the use of a wheelchair, but the participant was reluctant to use it.

The barriers to inclusion in this case were similar to case 2, taking into account that the two children were siblings and attended the same institution. The level of teacher discomfort in this case was higher compared to case 2. A greater number of recurrent complaints were reported concerning: laziness, making the least effort finding his illness as an excuse, lack of concentration, lack of motivation. The child also scored low in socialization, he remained isolated, and the only teacher with whom he reported a certain degree of empathy was the physical education teacher. The emotional state of the mother worried the team of the institution and was reflected in a lower participation and interest in the academic processes of her children. After the study, the child cognitively presented a social functional level of expressive and comprehensive language and was able to follow instructions; however, he still presented difficulties in addressing school issues. In the motor dimension, he could make short trips in the various rooms of the house, but, being affected by knock-knee, he suffered from joint pain and fatigue. At the socio-affective level, adequate relationships with the peers, mother and people from the family nucleus were reported. He was able to manage money and to perform some daily chores at home. In the school context, the child was helped by a team of support professionals and some teachers who made the curricular adjustments.

3.4. Case 4

Case 4 was the only female participant. Tables 10 and 11 present the results of the cognitive performance profile through the application of tests. The child showed an average IQ, with average scores for most scales except for processing speed, which revealed to be particularly low. These difficulties, added to failure in tracking tasks as well as a poor execution of motor tasks in a given time, could be associated with the phenotype of her

disease and the medical implications entailed. From a cognitive point of view, a greater commitment was observed in focused attention, thus affecting her working memory, especially in the visual channel. Her praxis, despite preserving the ideational and ideomotor systems, presented difficulties due to articular stiffness, which limited activities connected to precision and writing. It was necessary to work on mental and cognitive flexibility to carry out activities that required the ability to reason and to solve problems.

Table 10 – *WISC-IV Score Summary - Case 4*

Scale	Sum of scaled scores	Composite Score	Percentile Rank	90% Confidence Interval	Qualitative Description
Verbal Comprehension	32	102	55	96-108	Average
Perceptual Reasoning	29	98	45	92-105	Average
Working Memory	20	99	47	93-106	Average
Processing Speed	8	68	2	64-79	Extremely Low
Full Scale (Total IQ)	89	91	27	87-95	Average

Note: Sum of scales and obtainment of the IQ.

Table 11 – *Neuropsychological protocol - Case 4*

Domains						Scores			
Attention	Memory	Language	Gnosis	Praxis	EF	Test	Raw	Percentile	
	x		x	x	x	The Rey-Osterrieth Complex Figure	Copy	22	10
							Memory	19	50
x			x		x	The Stroop Color and Word Test	Word	38	< 5
							Color	27	< 5
							Word/Color	14	< 5
							Interference	-1.78	45

						x			Wisconsin Card Sorting Test-Modified (M-WCST)*	CC	14	25
										PM	11	< 5
										TM	19	15
										% PM	58%	10
x									Trail Making Test (TMT-A)	Time	44"/60"	10
										Errors	0	WS
x	x								Trail Making Test (TMT-B)	Time	94"/150"	< 5
										Errors	0	WS
x	x					x	x		Symbol Digit Modalities Test (SDMT)	Correct Score	18	25
	x	x							Token Test-Reduced version	Total	34	65
										Total number	201	< 5
										Total hits	86	5
										Total omissions	0	80
										Total commissions	1	70
x									D2 Test of Attention	Largest	19	< 5
										Least	9	5
										Effectiveness	200	< 5
										Concentration	85	15
										Fluctuation rate	10	25
										F Phoneme	2	10
										A Phoneme	5	15
									Verbal Fluency Test: Phonological Verbal Fluency Test	S Phoneme	1	< 5
										M Phoneme	5	15
										R Phoneme	4	15
										P Phoneme	4	10
									Verbal Fluency Test: Semantic Verbal Fluency Test	Animals	4	< 5
										Fruits	5	< 5
										Ceiling element	132	WS
									Peabody Picture Vocabulary Test III (PPVT-III)	No. Errors	26	WS
										Total	106	30

x	Learning	22	25
	Test de Aprendizaje y Memoria Verbal Infantil (TAMV-I)**	Memory delayed recall	5 < 5
		Recognition	11 40

Average: P_c 50; Normal Average: P_c 25 to P_c 75; Low Average: P_c < 25; High Average: P_c > 75; WS: Without Score.

* CC: Correct categories; PM: Perseverative Mistakes; TM: Total Mistakes; % PM: % Perseverative Mistakes

** Spanish version

As a result of the analysis of the interviews in the school context, it was found that most of the teachers agreed that the child depended on the support assistant in the academic subjects and presented an ambivalent behavior in class, as sometimes she was observed to be tired and lazy (possibly because of her sleep apnea), while, at other times, she was active, distracted, and preferred to play than pay attention. There were difficulties in walking and mobility due to the recent surgeries. Reasonable adjustments were made in the Spanish evaluation processes because the child was frustrated by having to write fast due to claw hand. Evaluations were made verbally and the use of a tablet was considered in the future. Her visual ability was compromised, the courses that were most difficult for her were English and Mathematics, since errors were observed in the position of the numbers and she required support from the assistant to manipulate the geometry instruments. She did not like to be treated differently with respect to her peers despite having difficulty in complying with the figure of authority.

Concerning her strengths, she showed to have a good development of comprehensive and expressive language, a fluent communicative capacity with respect to the knowledge of the environment and the explanations of causal relationships. In the motor dimension, she responded to most self-care activities and she was functional in conducting daily chores at home and at school. Concerning her socio-affective development, she had a positive perception of herself and an adequate pattern of relationship with both peers and adults. A good performance was reported in the school environment and the institution had an interdisciplinary team that knew the case, followed her and actively worked on finding reasonable accommodations to her condition, as well as having a support professional exclusively dedicated to her and to her needs.

3.5. Profile of reasonable needs for accommodation

The profile of needs was aimed to point out the barriers identified from the results of the analysis of the different sources of information (neuropsychological assessment, family interview and school context interview) to propose the needs for care of the cases in the school context, as an implementation of the public policy of Decree 1421 (Ministerio de Educación Nacional, 2017; see Tab. 12 for details). The common factors found, from the results in relation to the profile of needs in support of the inclusive education process for the four case studies examined, are set out below (refer to Tab. 13).

Table 12 – *Profile of Needs for Inclusive Education in MPS: Barriers*

Dimension	Barriers to inclusion
Cognitive	<p>Cognitive processes of attention, memory and flexibility that require strengthening, associated with a history of development and learning.</p> <p>Impairment of the visual and auditory attention due to conditions of the disease.</p> <p>School absence and lack of stimulation in the home context can widen the development gap that implies delays in the learning processes.</p>
Motor	<p>Patients present limitations associated with the basic diagnosis both in fine and gross motor skills.</p> <p>Speed of response and execution in tasks of a fine motor character are limited.</p> <p>Existence of pain, fatigue due to bone and joint condition.</p> <p>Limitation of mobility and locomotion due to initial diagnosis.</p> <p>Lack of supportive therapies (physical and occupational) in most cases.</p> <p>Limitations in physical activities that you can do at school due to the child's condition (wheelchair, oxygen, fatigue, among others)</p>
Socio-affective	<p>Possible protection of the family or lack of clarity in the responsibilities that the child is able to fulfill.</p> <p>In some cases difficulties in the expression and emotional regulation of the boys or girls.</p> <p>Limited relationship with peers.</p>

School	<p>Lack of knowledge of the educational system of the disease, as well as of the particular academic community.</p> <p>Compliance with the registration of curricular adjustments, but difficulties in its execution.</p> <p>Institutional infrastructure inadequate for the mobility and comfort requirements of children.</p> <p>Poor teacher training in inclusive pedagogical strategies and universal learning design.</p> <p>Few support professionals in relation to the number of cases of students with Special Educational Needs (SEN).</p> <p>Lack of knowledge of the family environment of how to carry out school reinforcement.</p> <p>Lack of knowledge of teachers about strategies for adjusting to the educational needs of the case.</p> <p>In the institutions, a program and process has not been consolidated within the inclusive education framework that materializes the government's indications beyond complying with formats.</p>
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Note: Barriers to inclusion identified from the analysis of interviews with mothers and staff of the school institution.

Table 13 – Profile of Needs for Inclusive Education in MPS: Reasonable Accommodation Guidance

Dimension	Accommodation to inclusion
Cognitive	<p>Enrichment of lexicon, expand exposure opportunities to varieties of the social and cultural context.</p> <p>Constant stimulation of the visual and auditory channels to improve the child's attentional span.</p> <p>Expand exposure to information of a cultural and academic nature and of particular interest to the child (documentary-type videos, children's literature).</p> <p>Stimulation activities considering the limitations in the visual and auditory sphere and conditions of joint stiffness, tasks that require attention to details, discrimination, tracking or sequencing, limited in time.</p> <p>Extend times for the execution of tasks.</p> <p>Children require information to be presented through augmentative and alternative means.</p> <p>Strengthen processes of adaptation and adjustment to the demands of tasks with an increasing level of complexity.</p>

Motor	<p>Due to the effect of the baseline diagnosis, the child can easily experience fatigue and may require additional time to complete activities (joint stiffness), which means that the speed to perform certain movements is lower than the average for children of comparable age.</p> <p>It requires alternatives for the writing process as the child progresses in academic degrees.</p> <p>Provide resources, pedagogical and school material conditioned to the child's characteristics (type of pencil, size of materials).</p> <p>Due to the limitations of movement in environments external to those of trust, derived from restrictions in relation to the child's basic pathology, generating activities or educational outings and cultural opportunities where children have facilities for access and mobility should be promoted.</p>
Socio-affective	<p>Children require support in self-care activities that are more physically demanding due to their health condition.</p> <p>The child requires support and accompaniment in his/her movements.</p> <p>Support in consolidating daily routines and responsibilities according to the child's age.</p> <p>Receive recognition and praise for children's daily achievements from both family members and the school environment.</p> <p>Provide the opportunity to meet people in environments other than school and family, which can contribute to the development of social skills for the beginning of relationships.</p> <p>Maintain spaces for sharing not only concerning responsibilities and care, but also focused on fun and recreation with family members.</p> <p>Expand the repertoire of social skills to interact in settings other than the family context.</p> <p>Learn strategies for expression and emotional regulation.</p>
School	<p>Improve communication channels between family and school to accompany as a team and carry out appropriate reinforcements.</p> <p>Assistive technology devices to improve the inclusive aspects of learning environments.</p>

Note: Guidance for the preparation of reasonable accommodation in the cases analyzed.

4. Discussion

Only a handful of studies have been conducted concerning inclusive education in children with Mucopolysaccharidosis (MPS), particularly in the Colombian context. The inclusion of the school, from an educational and neuropsychological point of view, as well as its adaptation to the needs of the child-adolescent population (Castañeda-Ibáñez & Acosta-Barreto, 2016), including the caregivers, family and the training for teaching staff, should be promoted and advised.

The contribution of neurosciences to education has shown some evidence over the past years so that the knowledge of the brain, of neurodevelopment, of the cognitive processes and learning, as well as of the relationship with the functioning and neurological characteristics associated with some syndromes, has allowed a more efficient orientation to appropriate educational actions (Martín-Loeches, 2015; Castañeda-Ibáñez *et al.*, 2017). In this sense, the neuropsychological evaluation is a valuable procedure in the identification of the learning possibilities of children and adolescents with MPS.

MPS IV-A, more specifically, shows a decrease, at a cognitive level, in attentional function, working memory and school reading-writing skills, as referred to in previous studies (Castañeda-Ibáñez *et al.*, 2017; Ibáñez Castañeda *et al.*, 2017). These are related to the execution of tasks due to its slow processing speed and characteristics of the disease, such as claw hand, joint stiffness and corneal opacity, which impair the learning processes involving other cognitive processes, such as fine praxis. However, for inclusive education it is necessary to characterize each case in order to be able to develop, together with the teaching team and support professionals from educational institutions, the curricular adaptations or reasonable adjustments that allow each participant to achieve learning.

Since MPS IV-A is the most frequent type of MPS in Colombia, an updated knowledge of the clinical and neuropsychological profile is necessary (Erazo-Narváez *et al.*, 2020) in order to better understand its cognitive features and to be able to carry out better curricular adaptations in the school context and in their respective inclusion in terms of educational psychology and neuropsychology. It is corroborated that knowledge concerning MPS in the educational context is practically nil, which highlights once again the need to train teachers in strategies for the care and pedagogical support of diverse populations (Puentes-Tellez *et al.*, 2020).

In particular, as pointed out by Paz-Lourido and colleagues (Paz-Lourido, Negre, De la Iglesia, & Verger, 2020), patients with rare diseases in school age often suffer from isolation, stigma or discrimination, reducing their educational opportunities due to the conditions that their education requires. The medical treatment these patients are exposed to, as well as the constant visits to health professionals and the effects of both the disease and treatment, generate an invisibility of this sector of the population in the educational context. However, research showed that teachers are generally willing and have a positive attitude towards inclusive education, but they do not have enough preparation to carry it out, which seems to be associated

with gender, previous experiences with the population and a higher level of study (Tárraga Mínguez, Grau Rubio, & Peirat Chacón, 2013; Álvarez Castillo & Buenestado Fernández, 2015; Abellán & Sáez-Gallego, 2020).

The need for teacher training for inclusive education is reported by several authors both in Latin America and in Europe as well as the need in recognizing the importance of public policies for the care of people with orphan diseases (The European Commission expert group on rare diseases – EURORDIS, 2018). This should be conducted through documentary reviews, proposals for a pedagogical approach and key elements, where the attitude of the teacher plays a fundamental role in really carrying out inclusive practices (Del Barrio & Castro, 2008; Loizidou-Ieridou, 2017; Herrera, Parrilla, Blanco, & Guevara, 2018; Luna González, 2019).

In inclusive education processes for patients with rare diseases, the importance of the impact of the disease on their school adjustment has been highlighted, expressed as a low motivation for achievement, a decrease in social competence, a decrease in autonomy and low self-esteem, which affects their quality of life (Tejada-Ortigosa, Flores-Rojas, Moreno-Quintana, Muñoz-Villanueva, Pérez-Navero, & Gil-Campos, 2019). In the cases of the present study, different dynamics were found in the educational contexts, families and schools involved, as in contexts outside the knowledge and management of the disease. Alfaro Consuegra and Negre Bennasar (2019) and Castro Zubizarreta and García-Ruiz (2014) collected the voice of relatives and teachers of children with rare diseases, who pointed out the importance of the family as a facilitating agent of communication between the health service and education, likewise the positive effect of building collaborative relationships between the family, the school, and health professionals for school adaptation.

Esteves Fajardo, Chavez and Gárces Gárces (2017) and Fernández Hawrylak and Grau Rubio (2014) pointed out the importance of the school as a socializing agent for this sector of the population and highlighted the collaborative work that should be structured between family and school based on the mutual knowledge of the needs, interests, tastes and desires of children with rare diseases, in terms of learning, fun and socialization. For the cases of this study, reaching the establishment of a collaborative working relationship for the well-being of children, implied expanding the communication alternatives between school and family, in order not only to gain knowledge of the characteristics of the disease but also knowledge of the characteristics of each individual student (Linertová, González-Guadarrama, Serrano-Aguilar, Posada-De-la-Paz, Péntek, Iskrov *et al.*,

2019; Luna González, 2019; Manjarrés Carrizalez, & Velez, 2019).

5. Conclusions

This study shows that in the educational institutions that were accessed, knowledge about MPS was scarce. The nature of the condition itself of being a rare disease allowed us to recognize the findings as an important input for families and institutions that face day by day monitoring of the development and learning processes of these children. In the cases of the present study, the institutions were oriented to the elaboration of the Individual Plans of Reasonable Adjustments (PIAR) to respond to the demands of the educational system, which does not necessarily guarantee inclusive practices in the classroom. Families historically search for the best conditions for the education of their children, with previous experiences of difficulty with both the health system and the educational system, but they are also unaware of the details of the norm that poses alternatives for action to the right to education for their children.

Among the limitations of the study was the lack to generalize the neuropsychological results obtained due to the population sample, the barriers in the educational and psychological field, as well as the norm to help school inclusion. These processes should be applied to longitudinal studies and well as the use of validated instruments in the Colombian context to get closer to the cognitive profile of the participants with MPS in the country. The use of evaluations of academic skills in conjunction with neuropsychological evaluations to know school performance was also highlighted. In the future, this type of study may contribute to the creation of educational and school inclusion policies for rare, orphan and low prevalence diseases, not only in the Colombian but also Euroamerican context.

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