Functional assessment of children and adolescents with autism spectrum disorder in Argentina: ICF-ASD multicenter study

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ABSTRACT

Introduction. Autism spectrum disorder (ASD) is characterized by difficulties in social communication and repetitive and stereotyped behaviors. In addition to the diagnostic category, the activities performed by children and adolescents and their social involvement are the main aspects to be considered according to the International Classification of Functioning, Disability, and Health (ICF) proposed by the World Health Organization to describe health status.

In a previous study, we developed the first version of a pediatric tool based on the ICF called ICF-ASD for the functional assessment of children and adolescents with ASD to capture functional characteristics adapted to our cultural setting. Our subsequent objective was to apply the ICF-ASD in a multicenter format to assess children and adolescents from different regions, review, and update it, and identify barriers and facilitators.

Population and methods. The ICF-ASD version 1.0 was administered to children and adolescents younger than 16 years with a confirmed diagnosis of ASD (as per DSM-5 criteria), who were receiving follow-up at 5 children's health centers across Argentina.

Results. Version 2.0 of the ICF-ASD was obtained, which included 34 categories (10 under body function, 15 under activities and participation, and 9 under environmental factors). A functional profile was developed for the whole sample (n = 308).

Conclusions. The updated version of the ICF-ASD helps to standardize and systematize the collection of necessary data for an adequate follow-up of children and adolescents with ASD at a national level. It also allows to identify barriers to overcome and facilitators to be generalized.

Keywords: autism spectrum disorder; International Classification of Functioning, Disability and Health; disability assessment; child; adolescent.

doi: http://dx.doi.org/10.5546/aap.2023-10171.eng

To cite: Napoli SB, Vitale MP, Urinovsky MG, Fassero MP, et al. Functional assessment of children and adolescents with autism spectrum disorder in Argentina: ICF-ASD multicenter study. Arch Argent Pediatr. 2024;122(5):e202310171.

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National Registry of Health Research: IN005734. National Ministry of Health.

Funding: None.

Conflict of interest: None.

Received: 8-1-2023 Accepted: 2-6-2024



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INTRODUCTION

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by difficulties in communication and socialization and repetitive and stereotyped behaviors.¹ Its overall prevalence is 1–2%,² and its diagnosis is based on the specific criteria established by the DSM-5/ICD-10.^{3,4} Although a categorical diagnosis is essential, it should be complemented by a functional description to understand daily performance and ensure appropriate interventions.

In 2001, the World Health Organization (WHO) proposed using the International Classification of Functioning, Disability, and Health (ICF)⁵ and, in 2007, the ICF version for children and youth (ICF-CY)⁶ was proposed to approach disability from a biopsychosocial perspective, emphasizing functioning and the fundamental role of the environment. Functioning, that is to say, everything that a person does in their daily life, including social involvement, provides more information to understand the course of children and adolescents with ASD than diagnosis itself.⁷

Analyzing the extent of involvement of children and adolescents with ASD and their families in the community and the environmental factors that prevent or facilitate such involvement is critical to ensure the exercise of their rights. Therefore, collecting functioning data to complement diagnostic data is crucial to guide health and social policies that ensure inclusion, diversity, and social equity.⁸⁻¹⁰

The implementation of the ICF is challenging due to its length, which is why abbreviated versions called "core sets" have been developed for various health and neurodevelopmental conditions,¹¹ which allow the development of profiles summarizing functional skills and limitations, as well as environmental factors that help or hinder daily functioning.

In 2019, we developed an Argentine tool called ICF-ASD, based on the core set for ASD¹¹ and supported by the teams of Bölte (Sweden) and Schiariti (Canada). This tool was used to describe the functional aspects of children and adolescents with ASD in clinical settings in a sample of 100 children and adolescents.¹²

After that initial study, we proposed its administration in a multicenter format, with the following objectives: 1) to assess the feasibility of use in healthcare centers in Argentina with teams with varying degrees of experience, 2) to review and improve the tool with experience in different contexts, 3) to obtain a functional profile of the study population with ASD, 4) to identify functional barriers and facilitators in the different regions.

This article describes the process and initial results obtained in a multicenter study.

POPULATION AND METHODS Type of study

This was a descriptive, cross-sectional study with prospective data analysis.

Population

Children and adolescents with a confirmed diagnosis of ASD (as per the DSM-5 criteria), younger than 16 years, who attended the scheduled follow-up appointment at 5 participating healthcare centers: Department of Interdisciplinary Neurodevelopment Clinics, Hospital de Pediatría S.A.M.I.C. Prof. Dr. Juan P. Garrahan; Child Development Team of Hospital Provincial de Neuquén Dr. Castro Rendón; Department of Child Development, Unit of Mother and Child of San Luis; Unit of Mother and Child of Hospital Nicolás Avellaneda de Tucumán; and Team of the PROATEA Program of the Bahía Blanca Health Region I.

All patients were included in the sample in a consecutive manner. No exclusion criteria were established, except for refusal to participate. Parents were asked to give their informed consent.

Considering the number of children and adolescents who attend each center annually for follow-up, the sample size selected by convenience was estimated at n = 300.

The following population data were recorded: age, sex, education of children and adolescents and their caregiver, associated medical conditions, associated developmental disorders, ASD severity (level 1, 2, or 3 as per the DSM-5),⁵ socioeconomic indicator: unmet basic needs (UBNs).

Procedure

During the first month, all teams were trained on how to administer the ICF-ASD, version 1, which is made up of 32 ICF categories (10 under body functions, 15 under activities and participation, and 7 under environmental factors) and the corresponding instruments to assess each category. The initial tool was thus established (version 1.0).¹²

The instruments proposed to measure each

category, commonly used by investigators in the different centers, require a single scoring criteria and transformation into ICF qualifiers.

A pilot test was then performed in consultations shared by 2 administrators, each one scoring independently, and an inter-observer reliability analysis was performed using Cohen's kappa coefficient statistical test. A value > 0.60 was considered acceptable and > 0.80, excellent.

The ICF-ASD was subsequently administered in the consultation with the child/adolescents and their family. An individual profile of functioning was obtained, detailing the problem level of each of the categories and the extent to which environmental factors are facilitators or barriers for that individual, with the objective of guiding interventions according to their particular situation. Group functional profiles were then developed, which made it possible to analyze categories and facilitators or barriers to participation in general.

When restrictions due to the pandemic prevented in person consultations, the ICF-ASD was administered via teleconsultation, after verifying the availability of devices (computer, cell phone) and Internet connection.

Data were collected in the RedCap database. The RStudio software was used for statistical analysis. Summary measures were described: average and 95% confidence interval (CI) or median and range or frequency of categories.

During the process, online team meetings were held to share quantitative and qualitative aspects of this new assessment perspective. A brief questionnaire was designed for parents (anonymous) to assess their satisfaction after the protocol was administered. Interventions were indicated for the management of any difficulty detected during the assessment.

Finally, given the possibility that both parents and evaluators could include issues of concern not contemplated in the original proposal, categories were considered for inclusion with the agreement of 75% of the evaluators. Assessment tools were modified when acceptable interobserver agreement was not obtained. Therefore, the new ICF-ASD version 2.0 was made up of 34 categories (10 under body function, 15 under activities and participation, and 9 under environmental factors), as shown in *Table 1*.

The Supplementary material provides more details on the methodology used for the development of both ICF-ASD version 1.0 and the current ICF-ASD version 2.0.

This research study was carried out with a

Multiple Health Research Scholarship for 2021– 2022 granted by the National Ministry of Health of Argentina. The study was evaluated and approved by the Associated Direction of Research and Teaching, the Hospital Ethics Committee, the Board of the hospital in charge of coordinating the study, and each center's committee.

RESULTS

Between December 2021 and October 2022, 327 patients were invited to participate; all started the assessment, but only 308 completed it.

Feasibility

The administration of the ICF-ASD protocol was completed in 94% of the cases, showing its feasibility in terms of duration and comprehension of each item. Concern for an acute medical problem or family conflict situation were the causes associated with the interruption.

Instrument adequacy

The ICF-ASD content was modified based on the need to cover new categories considered relevant to the team and families, with acceptable inter-observer reliability measures (*Table 1*).

Functional profile

The demographic characteristics of the study population are described in *Table 2*.

Table 3 shows the frequency (%) of problems with body functions, activities and participation, and environmental factors for the entire sample (n = 308). *Figure 1* shows the profile for the sample.

In relation to body functions, we noted that most parents (78.7%) reported problems of varying severity in terms of attention, while sleep was a problem for 30%. The impact of sensory difficulties on functioning was moderate to complete in 38%. Expressive and receptive language were problems in almost all cases (*Table 3*).

In relation to activities, behavior management was a moderate to severe problem in almost half of the cases. Difficulties in sphincter control were reported in more than half, while feeding was a problem for most families, with varying levels of severity (64%), including selectivity, rejection of food groups, overweight, or obesity.

Schooling was a problem for 45% for reasons such as reduced school hours (40.4%), lack of aides (36%), poor communication with therapists (3.5%), harassment (15.8%), or negative attitudes of teachers (30.7%).

TABLE 1. ASD-ICF tool, version 2.0

	Body functions (b)					
Category	/	Mea	suring instrume	ent		
b117	Intellectual functions	CAT/CLAMS	WPPSI	S. Binet	KBIT	Leiter
b125	Intra-personal functions	VAS (parents)				
b134	Sleep functions	VAS (parents)				
b140	Attention functions	VAS (parents)				
b156	Perceptual functions	VAS (parents)				
b1670	Mental functions of receptive language	CLAMS	CELF	GARDNER	PLS	VABS
		(0	Communication)			
b1671	Expressive language	CLAMS	CELF	GARDNER	PLS	VABS
		(0	Communication)			
b7602	Coordination	VAS (parents)				
b7652	Mannerisms	ADI-R (item 77)	ADOS			
b7653	Complex stereotypies	ADI-R (item 78)	ADOS			
	Activ	vities and participation (d)				
d110	Watching	ADI-R (item 50)	ADOS			
d115	Listening	ADI-R (item 46)				
d130	Copying	CARS (item 2)				
d155	Acquiring skills	Activities and participation (d) ADI-R (item 50) ADOS ADI-R (item 50) ADOS ADI-R (item 46) CARS (item 2) VABS (Activities of daily living) or CARS (item 6) Observation/interview ges ADI-R (42, 43, 44 y 45) ADOS ADI-R (item 35) ADOS VAS (parents) VAS (parents) VAS (parents) VASS (Interpersonal relations)				
d250	Managing one's own behavior	CARS (item 6)				
d330	Speaking	Observation/interview				
d335	Producing nonverbal messages	ADI-R (42, 43, 44 y 45)	ADOS			
d350	Conversation	ADI-R (item 35)	ADOS			
d530	Toileting	VAS (parents)				
d550	Eating	VAS (parents)				
d720	Complex interpersonal interactions	VABS (Interpersonal relation	s)			
d7500	Informal social relationships	PEDSQL Social functioning	1			
d815	Preschool education	VAS (parents)				
d820	School education	VAS (parents)				
d920	Recreation	VABS (Play and leisure time	e)			
	En	vironmental factors (e)				
e125	Technology for communication	Interview				
e140	Products and technology for culture.	VAS (parents)				
	recreation and sport					
e310	Immediate family	Family APGAR				
e355a	Health professionals	VAS (parents)				
e355b	Therapists	Interview				
e430	Individual attitudes of people in position	s VAS (parents)				
	of authority (school authorities)					
e455	Individual attitudes of health profession	als VAS (parents)				
e5502	UCD	Interview				
e555	Parent associations	VAS (parents)				
e5800	Health services	Interview				

The tool is made up of the instruments proposed to assess each functioning category in the ICF-ASD, version 2.0. Such instruments (tests, questionnaires, test items, visual scales, and specific questions addressed to families) were carefully selected by the team and their inter-observer reliability was tested (see Annex). Some cases require the use of a single instrument per category; as shown in the table, options are proposed so that each team can select the instrument best suited to their clinical experience.

CAT/CLAMS: Clinical Adaptive Test/Clinical Linguistic and Auditory Milestone Scale, ADI-R: Autism Diagnostic Interview-Revised, ADOS-2: Autism Diagnostic Observation Schedule-2, WPPSI: Wechsler Preschool and Primary Scale of Intelligence, CARS: Childhood Autism Rating Scale, VABS: Vineland Adaptive Behavior Scales, VAS: Visual analogue scale, Leiter: intelligence test, KBIT: Kaufman Brief intelligence test, PedsQL: Pediatric Quality of Life Inventory, S.Binet: Stanford-Binet Intelligence Scales, Gardner: Gardner Expressive/Receptive One Word Picture Vocabulary Test, PLS: Preschool Language Scale, CELF-4: Clinical Evaluation of Language Fundamentals 4, APGAR: Adaptability, Partnership, Growth, Affection, and Resolve, UCD: Unique certificate of disability.

TABLE 2. Sample characteristics

Sample size	n = 308	
Age in months, median (range) < 6 years % (n) 6–16 years % (n)	82 (28, 192) 41.2 (127) 58.8 (181)	
Median age at the time of ASD diagnosis (range) Girls Boys	40 (20, 168) 44 (23, 111) 39 (20, 168)	
Sex % (n) Boys Girls	81.2 (250) 18.8 (58)	
Unmet basic needs % (n)	8.8 (27)	
Severity level (DSM-5) % (n) I Requires support II Requires substantial support III Requires very substantial support	32.8 (101) 38.3 (118) 28.9 (89)	
Language % (n) Yes No	71 (219) 29 (89)	
Yes Regular school Special school Education and therapy center Regular school with aides No, overall No (< 42 months)	94.4 (291) 45.4 (140) 11.8 (36) 3.6 (11) 33.7 (104) 5.6 (17)	
Associated medical conditions *% (n) Sleep problems Obesity Genetic disorder Chronic condition Epilepsy	52 (159) 25.2 (38) 25.8 (39) 12.6 (19) 6.6 (10) 9.3 (14)	
Associated developmental conditions **% (n) Overall developmental delay / intellectual disability / unspecified intellectual disability Developmental coordination disorder Anxiety Language disorder Behavioral disorder Attention deficit hyperactivity disorder (ADHD) Hearing impairment Learning disability	67.9 (209) 52.2 (109) 4.8 (10) 4.8 (10) 16.3 (34) 8.1 (17) 3.8 (8) 1.4 (3) 5.7 (12)	
Caregiver's level of education % (n) Illiterate (never attended school) Incomplete primary education Complete primary education/incomplete secondary education Complete secondary education/incomplete tertiary or university education Complete tertiary or university education	0.7 (2) 1 (3) 27.9 (86) 49 (151) 21.4 (66)	
Place of origin % (n) CABA (Autonomous City of Buenos Aires) Bahía Blanca (Buenos Aires) Tucumán San Luis Neuquén Greater Buenos Aires Other provinces	8.8 (27) 6.8 (21) 13 (40) 16.6 (51) 10.4 (32) 40.3 (124) 4.2 (13)	

Consultation modality % (n)	
In person	90 (277)
Teleconsultation	10 (31)
UCD (unique certificate of disability) % (n)	86 (265)
Area % (n)	
Rural	6.5 (20)
Urban	93.5 (288)
Treatment % (n)	
Yes	73.2 (225)
No	26.8 (83)
Provided in the public sector	15.2 (47)
Provided by a group health plan funded by a labor union	71.4 (220)
Provided by the private sector	13.4 (41)
Satisfaction survey % (n)	
Very useful (topics addressed)	90 (277)
Adequate consultation time	99.6 (307)

*Associated medical conditions: values described as % were estimated based on the number of children and adolescents with associated medical conditions, which accounts for 52% of the overall sample. A single child or adolescent may have more than 1 associated medical condition.

*Associated developmental conditions: values described as % were estimated based on the number of children and adolescents with associated developmental conditions, which accounts for 67.9% of the overall sample. A single child or adolescent may have more than 1 associated developmental condition.

ASD: autism spectrum disorder.

Barriers and facilitators

Products and technology for communication (e.g., pictograms) were considered a barrier due to lack of use or partial use in 60%; this was similar in all regions (*Table 4*).

Close relatives were the main aides available to the family. We found regional differences in terms of follow-up by the treating pediatrician, whose absence (21% of the overall sample) was considered a barrier (*Table 5*). The attitudes of school authorities were considered facilitators in 58% of the cases, with minimal variations among schools (*Table 4*).

We found regional differences in access to treatment: 27% of the total sample did not receive therapies. Therapists were considered facilitators when their intervention was regarded as sufficient in terms of work hours and quality, addressed parents' concerns, and provided treatment strategies (*Table 5*).

Contact with parent associations was used by only 50% of the families, who considered it a facilitator. In 30% of the centers, the officers working for the labor union health plan were considered barriers because they hindered access to aides; this was similar in all the centers. Having a unique certificate of disability was considered a facilitator. A report with the outcomes of the assessment was given to each family.

DISCUSSION

This multicenter study is the first description of the profile of functioning for an extended sample of children and adolescents in Argentina.

The use of the ICF-ASD version 2.0 helped to obtain a standardized description of functional skills and limitations and the role of environmental factors. This information is relevant to identify functional therapeutic goals and, in turn, plan environmental adaptations that facilitate social inclusion.¹³

The administration of the ICF-ASD took place in tertiary care clinical settings, both in person and via teleconsultation, which demonstrated its feasibility even in situations where long distance or isolation prevent an adequate followup of the course of this population.¹⁴ Common profiles were observed in body functions and in activities and participation across the different regions, with some differences in environmental factors. This was to be expected, since the tool's categories encompass universal clinical aspects and previously selected known environmental factors.¹² However, it was also possible to detect different aspects, the basis for planning specific

TABLE 3. Frequency % (n) of problems related to body functions, activities and participation, and environmental factors for the overall sample, n = 308

Category	/ Body functions		Qualific no prob	er 0 Iem	Qualifier 1 mild problem	Qualifier modera probler	r 2 te m	Qualifier 3 severe problem	Qualifier complete problem	4 Qualifie e not specifie	r8Qu edap	ualifier 9 not plicable
b117	Intellectual functions		10.2 (3	32)	4.9 (15)	8.1 (25	5)	2.3 (7)	6.5 (20)	68 (209	9)	
b125	Intra-personal functions	5	25 (7	7)	27.9 (86)	29 (89)	12.3 (38)	2.9 (9)	2.9 (9)	
b134	Sleep functions		65.6 (2	02)	16.5 (51)	8.4 (26	6)	5.2 (16)	2 (6)	2.3 (7)	
b140	Attention functions		18.5 (57)	32 (99)	29 (89)	14.9 (46)	2.7 (8)	2.9 (9)	
b156	Perceptual functions		33.1 (1	02)	26 (80)	21 (65)	12 (37)	5 (15)	2.9 (9)	
b1670	Receptive language		10.7 (3	33)	27.5 (85)	37.9 (11	7)	17 (52)	4 (12)	2.9 (9)	
b1671	Expressive language		5 (15	5)	18 (56)	49 (151	1)	22.3 (69)	3.4 (10)	2.3 (7)	
b7602	Motor coordination		56 (17	'2)	19 (59)	15 (46)	7 (22)	1 (3)	2 (6)		
b7652	Tics and mannerisms		44 (13	35)	24.5 (76)	21.5 (6	6)	8 (25)	2 (6)			
b7653	Stereotypies and motor perseveration		27.5 (8	35)	35 (108)	29 (89)	6.5 (20)	2 (6)			
Categor	y Activities and participation	on	Qualifie	er O	er 0 Qualifier 1 Qualifier 2 Qualifier 3 Qualifier 4		4 Qualifie	r8 Qu	ualifier 9			
d110	Watching		17 (5	2)	45 (139)	32 (99)	3.7 (11)	0.3 (1)	2 (6)		
d115	Listening		18.2 (56)	42.4 (131)	33.1 (10)2)	4 (12)	2.3 (7)			
d130	Copying		31.8 (9	98)	32.1 (99)	25.7 (7	9)	7.1 (22)	1 (3)	2.3 (7)	
d155	Skill acquisition		6.7 (2	0)	32 (99)	41.8 (12	29)	12 (37)	4.6 (14)	2.9 (9)	
d250	Managing one's own											
	behavior		16.9 (52)	33.1 (102)	37 (114	1)	11 (34)	1 (3)	1 (3)		
d330	Speaking		34 (10)5)	17 (52)	20 (61)	15.5 (48)	12.5 (39) 1 (3)		
d335	Producing nonverbal											
	messages		35.7 (1	10)	18.5 (58)	22.5 (6	9)	16 (49)	5.3 (16)	2 (6)		
d350	Conversation		4.2 (1	3)	21 (65)	25 (77)	4.2 (13)	1.6 (5)	1 (3)	. 43	3 (132)
d530	Toileting		44 (13	35)	18.1 (56)	16 (49)	14.3 (44)	6 (19)	1.6 (5)	
d550	Eating		36.4 (1	12)	22 (68)	19.5 (6	0)	13.7 (42)	8.1 (25)	0.3 (1)	
d720	Complex interpersonal interactions		6.2 (1	9)	17.5 (54)	61.3 (18	89)	12 (37)	1 (3)	2 (6)		
d7500	Informal relationships				00 ((00)				0.0 (10)	0 = (0)		
10.4 5	with friends		1.6 () 70)	22.1 (68)	45.2 (13	39)	21.1 (65)	3.3 (10)) 6.7 (21	1)	0 (10 1)
d815	Preschool education		24.7 ((6)	2.7 (8)	4.2 (13	3)	3.9 (12)	3.6 (11)	1.3 (4) 59	.6 (184)
d820	School education		30.5 (9	94)	6.8 (21)	6.2 (19))) ()	4.9 (15)	7.8 (24)	1.6 (5) 42	.2 (130)
d920	Recreation and leisure		5 (15) 	20 (62)	53.2 (16	o4)	17.6 (54)	1.7 (5)	2.5 (8)	
Category	Environmental factors	Mild barrier (1)	Moderate barrier (2)	Seve barrie (3)	re Complete er barrier (4)	No barrier/ no facilitador (0)	facilita (+1)	tor facilit) (+2	rate Substant ator facilitato) (+3)	ial Complete or facilitator (+4)	Not specified (8)	Not applicable (9)
e125	Products and technology	15	19.2	13.0	6 14	17.8	8.7	7.	5 2.9	1.3		
	for communication	(46)	(59)	(42) (43)	(55)	(27)) (23	3) (9)	(4)		
e140	Products and technology	7.5	6	10	2	17.7	14.9) 22	2 8	2.9	5	4
	for culture, recreation and sport	(23)	(19)	(31) (6)	(54)	(46)) (68	3) (25)	(9)	(15)	(12)
e310	Immediate family		18.2 (56)		1.7 (5)		79 (2	43)		1.1 (4)
e355a	Health professionals (pediatrician)	1 (3)	1 (3)	1 (3	6) 21.1 (65	5)11.6 (37)	7.6 (2	3) 21.5	(66) 14.7 (4	5) 17.6 (54	4) 2.9 (9)	
e355b	Health professionals	2.3	5.8	2.3	27	3.6	8.4	20.	9 18.2	9.9	1.6	
	(therapist)	(7)	(18)	(7)	(83)	(11)	(26)) (65	5) (56)	(30)	(5)	
e430	Individual attitudes	2.3	6.1	5.5	7.8	16.8	7.2	15.	1 21.7	14.6		2.9
	of people in positions of authority-school authorities	(7)	(19)	(17) (24)	(52)	(22)) (46	67)	(45)		(9)
e455	Individual attitudes	1.9	9.6	6.3	8.9	11.8	7.7	9.9	9 9.2	5.9	1.9	26.9
	of health professionals (labor union health plan)	(6)	(29)	(19) (28)	(37)	(24)) (30)) (28)	(18)	(6)	(83)
e5502	Legal policies		1	1.6 (36)	1 (3)			87.4 (26	69)		
e555	Associations and	5	1	,	,	49	10	12.	5 11.5	7	4	
	organizational services, systems and policies (parent association)	(15)	(3)			(151)	(31)) (39	9) (35)	(22)	(12)	
e5800	Health services, systems and policies	6.7 (21)	18 (56)	6.7 (21	5.6) (17)	5 (15)	14 (43)	29) (89	9 13 9) (40)	2 (6)		

This table shows the results described as % (percentage) of the level of problem in each functioning category. The ICF proposes classifying the severity levels of a problem using a generic scale (0-4%: no problem; 5-24%: mild problem; 25-49%: moderate problem; 50-95%: severe problem; 96-100%: complete problem; qualifier 8 is used when the category is not specified and qualifier 9, when it is not appropriate to qualify a certain category). For environmental factors, the same generic scale is used to determine the level of barrier or facilitator in each category.

Center (n)	Techno	ogy for commu	nication	Attitudes of school authorities			
	Facilitator % (n)	Barrier % (n)	Neutral % (n)	Facilitator % (n)	Barrier % (n)	Neutral % (n)	
San Luis (51)	25.5 (13)	72.5 (37)	2 (1)	56 (29)	18 (9)	26 (13)	
Neuquén (32)	15.5 (5)	65.5 (21)	19 (6)	60 (19)	22 (7)	18 (6)	
Tucumán (40)	22.5 (9)	55 (22)	22.5 (9)	50 (20)	35 (14)	15 (6)	
CABA + Greater							
Buenos Aires (151)	20 (30)	59 (89)	21 (32)	60 (91)	22 (33)	18 (27)	
Bahía Blanca (21)	23.5 (5)	47.5 (10)	29 (6)	66.5 (14)	9.5 (2)	24 (5)	
Other (13)	7.6 (1)	84.6 (11)	7.6 (1)	54 (7)	15.5 (2)	30.5 (4)	

TABLE 4. Technology for	communication and	attitudes of school	authorities: and	alysis b	y region
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Results are described as % (percentage) in each region in the categories technology for communication and attitudes of school authorities. Other (13): children who attended a health care center in the CABA but come from different regions across the country. n: number, CABA: Autonomous City of Buenos Aires.

TABLE 5.	Treating	pediatrician	and thera	nist availabili	tv: analv	sis b	v region
TABLE V.	neuting	pediatrolari	und unoru	pistuvunusin	iyi amany	313 0	y icgion

Center (n)	No follow-up by pediatrician % (n)	No therapists % (n)
San Luis (51)	6 (3)	17 (9)
Neuquén (32)	25 (8)	47 (15)
Tucumán (40)	30 (12)	10 (4)
CABA + Greater Buenos Aires (151)	25 (38)	28.4 (43)
Bahía Blanca (21)	4.7 (1)	28 (6)
Other (13)	23 (3)	46 (6)
Overall sample (308)	21 (65)	27 (83)

Results are described as % (percentage) in each region in the categories 355 a and b, which refer to the presence of a treating pediatrician and access to a health care team. Other (13): children who attended a health care center in the CABA but come from different regions across the country.

n: number, CABA: Autonomous City of Buenos Aires.

interventions, which are a benefit of using this type of tool.

The evaluation of performance promotes a person-centered model of care with a human rights approach.^{15,16} To this end, it is necessary to have accessible settings capable of providing support for the participation of all children and adolescents,^{17,18} in line with the current recommendations of family-centered interventions.^{19,20}

Although children and adolescents may share the same diagnosis of ASD, their functional capacity varies considerably; therefore, an assessment that considers this aspect will be more effective and comprehensive.^{21,22} The ICF-ASD helped to change healthcare providers' approach to a family-centered assessment, who appreciated the fact that their opinions were prioritized.

This multicenter study helped to consider environmental aspects, including the detection of situations of social isolation and the possibility of managing extra-family support networks, e.g., contacting parent associations. At an individual level, the ICF-ASD allowed to describe the profile of each child and adolescent and to easily identify skills, difficulties, and intervention goals; e.g., to indicate interventions to improve sleep problems. At a group level, it allowed to identify common difficulties, e.g., in access to treatment (e455), little use of technology for communication (e125), difficulty to organize recreation and leisure time (d920), which require interventions at the community level to improve participation.

As described in the bibliography, intervention goals should be organized around maximizing

Code	Category name	ICF qualifier								
	BODY FUNCTIONS						Imp	airm	ent	
						0	1	2	3	4
b117	Intellectual functions	4				8			_	
b125	Dispositions and intra-personal functions	4							_	\vdash
b134	Sleep functions	4							_	\vdash
b140	Attention functions	4					_		_	\square
b156	Perceptual functions	4							_	
b1670	Reception of language	4							_	
b1671	Expression of language	1								
b7602	Coordination of voluntary movements	1								
b7652	Tics and mannerisms									
b7653	Stereotypies and motor perseveration									
	ACTIVITIES AND PARTICIPATION (performance)					0	Imp 1	airm 2	ent 3	4
d110	Watching									
d115	Listening									
d130	Copying									
d155	Acquiring skills									
d250	Managing one's own behavior									
d330	Speaking									
d335	Producing nonverbal messages				_					
d350	Conversation									
d530	Toileting									
d550	Eating			_						
d720	Complex interpersonal interactions									
d7500	Informal relationships with friends									
d815	Preschool education				_					
d820	School education			_						
d920	Recreation and leisure				_					
			Facili	tator		Barrie			rier	
	ENVIRONMENTAL FACTORS	+4	+3	+2	+1	0	1	2	3	4
e125	Products and technology for communication									
e140	Products and technology for culture, recreation and sport									
e310	Immediate family									
e355	Health professionals									
e430	Individual attitudes of people in positions of authority									
e455	Individual attitudes of health professionals									
e5502	Legal policies									
e555	Associations and organizational services, systems and policies	<u> </u>								
e5800	Health services									

FIGURE 1. Functional profile for the entire sample

The most frequent problem level in each category is represented, taking the results for the total sample as a reference. For Activities and participation: P (performance) refers to what individuals do in their current environment. C (capacity) refers to what individuals do in a standard environment. In this case, performance was assessed. A higher number implies a greater difficulty. 8: corresponds to non-specified.

the potential for functioning, minimizing barriers, and optimizing the individual's "adaptation" to their environment,²⁰ which can be achieved with better training for healthcare providers, raising awareness among the general population and, in addition, guiding therapies according to the impact of the problem and not as a universal indication given by the diagnosis of ASD.²⁰

The attending pediatrician was considered a facilitator for most families; the importance of ensuring that longitudinal pediatric followup is accessible to all is emphasized. The ICF- ASD collected data on school experiences; in all analyzed regions, some were highly positive and others, negative. We consider it important to demand the participation of all children and adolescents in regular schools with the necessary aides, as this is positively valued by families and contributes to the objective of working towards inclusion.

Several advantages are recognized from the implementation of the ICF-ASD, including the standardization and systematization of information for the adequate follow-up of children and adolescents with ASD at a national level. The ICF-ASD helps to define essential functional aspects to suggest interventions, effectively allocate resources according to the level of problem represented in the functional profile categories, and advocates for the empowerment of families in decision-making and for inclusion in natural environments by detecting contextual barriers and facilitators.

Lack of data is a major barrier to decisionmaking and access to health care and specialized services for people with disabilities.¹³ As in other studies mentioned in the bibliography,⁷⁻¹⁰ using tools based on the ICF is feasible, which help to obtain data on functioning, considered as a third health indicator, complementary to mortality and morbidity.²³ Together, these 3 health indicators provide a comprehensive set of indicators for monitoring the performance of health strategies in health systems.²⁴

The limitations of this study relate to the time required for the assessment and the training necessary for its administration. Category selection may have left out some aspects relevant to some children and adolescents. The sample should be larger and include other regions in our country. Lastly, it is worth mentioning that the ICF-ASD is a live instrument and, as such, it is susceptible to review and improvement as it is used.

CONCLUSIONS

Adopting the ICF-ASD is feasible and provides data that are summarized in an individual or group functioning profile of children and adolescents; data that, until now, were not available in Argentina.

The ICF-ASD ensures a comprehensive approach, promotes care centered on the interests and preferences of children and adolescents with ASD and their families,^{25,26} and helps to detect barriers or facilitators to daily functioning. In short, it leads to improved health care processes, under a paradigm proposed by the WHO in line with the Convention on the Rights of Persons with Disabilities.²⁷ ■

Acknowledgments

We would like to thank participating investigators for their contribution to the care of study patients: Bárbara Gouguenheim, M.D., Juan José López Luro, M.D., Paula Pedernera Bradichansky, M.D., Pablo Cafiero, M.D., Celina Lejarraga, M.D., Emanuel Bellantonio, M.D., Laura Rodríguez, M.D., Anabella Escalante, M.D., Laura Cragno, B.S., Evoe Narcotti, B.S., Lourdes Castro Moyano, B.S., María del Carmen Liendo, B.S., María Eugenia Matías, B.S.

And we would also like to thank Pablo Cafiero, M.D., Paula Pedernera Bradichansky, M.D., and Juan José López Luro, M.D. for their critical review of articles.

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