

Using the Supports Intensity Scale – Children's Version with Children with Autism and Intellectual Disability

Karrie A. Shogren, Ph.D. Professor, Department of Special Education Co-Director, Kansas University Center on Developmental Disabilities Associate Director, Beach Center on Disability University of Kansas <u>shogren@ku.edu</u>

Support Needs Assessment

- As in the intellectual disability field, the autism spectrum disorder field has begun to focus on the role of individualized supports in classification and enhancing outcomes
- The Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) shifted classification of ASD from an array of five distinct developmental disorders to a three-level system based on the amount of support required in social communication and restricted, repetitive behavior
 - Level 3 designates the need for very substantial support
 - Level 2 the need for substantial support
 - Level 1 the need for some support



	Demographic Characteristics	Autism & I Disability	ntellectual (N = 2,124)	Intellectua Only (N	al Disability = 1,861)		
2	Variable	n	%	n	%		
	Gender						
-	Male	1,614	76.0	1,094	58.8		
	Female	474	22.3	725	39.0		
1	Missing	36	1.7	42	2.3		
-	Data Source						
	State ID/DD System	1,459	68.7	1,422	76.4		
	School District	665	31.3	439	23.6		
1	Age cohort						
	5-6	317	14.9	194	10.4		
	7-8	335	15.8	226	12.1		
	9-10	462	21.8	300	16.1		
	11-12	409	19.3	393	21.1		
	13-14	379	17.8	439	23.6		
	15-16	199	9.4	285	15.3		
	Missing	23	1.1	24	1.3		
	Student's intelligence level						
11	< 25 or profound	124	5.8	335	18.0		
	25-39 or severe	482	22.7	379	20.4		
	40-55 or moderate	776	36.5	544	29.2		
	55-70 or mild	632	29.8	523	28.1		
	Missing	110	5.2	80	4.3		



Findings

Children with ID-ASD tended to have:

- Lower exceptional medical support need scores
- Higher exceptional behavioral scores
- Similarly, the proportion of children with ID-ASD that had a rating of 2 or higher (the maximum score) on at least one item tended to be lower for medical but higher for behavior



	Respiratory care				
	Inhalation or oxygen therapy	0	1	2	[
	Postural drainage	0	1	2	
	Chest physical therapy	0	1	2	
	Suctioning	0	1	2	
ł	Feeding assistance				
	Oral stimulation or jaw positioning	0	1	2	
	Tube feeding (e.g., nasogastric)	0	1	2	
	Parenteral feeding (e.g., IV)	0	1	2	
	Skin care				
	Turning or positioning	0	1	2	
	Dressing of open wound(s)	0	1	2	
	Other exceptional medical care				
	Protection from infectious diseases due to immune system impairment	0	1	2	
	Seizure management	0	1	2	
	Dialysis	0	1	2	
	Ostomy care	0	1	2	
	Lifting and/or transferring	0	1	2	
	Eating disorders	0	1	2	
	Therapy services	0	1	2	
	Allergies	0	1	2	
	Diabetes management	0	1	2	
	Other(s) – List all that apply				5

Externally directed behavior			
Prevention of tantrums or emotional outbursts	0	1	2
Prevention of assaults or injuries to others	0	1	2
Prevention of property destruction (e.g., fire setting, breaking furniture)	0	1	2
Prevention of stealing	0	1	2
Self-directed behavior			
Prevention of self-injury	0	1	2
Prevention of pica (ingestion of inedible substances)	0	1	2
Prevention of suicide attempts	0	1	2
Sexual behavior			
Prevention of sexual aggression	0	1	2
Prevention of non-aggressive but inappropriate sexual behavior	0	1	2
Other exceptional behavioral concerns			
Prevention of wandering	0	1	2
Prevention of substance abuse	0	1	2
Maintaining mental health treatments	0	1	2
Prevention of truancy	0	1	2
Other(s) – List all that apply			
	0	1	2



Reliability Indices

Age	Autism & I	ntellectual D	Disability	Age	Intellectu	al Disability	' Only
Cohort	Construct	Alpha	Omega	Cohort	Construct	Alpha	Omega
Total	HLA	.910	.909	Total	HLA	.943	.944
(Item)	CNA	.934	.936	(Item)	CNA	.940	.941
	SPA	.924	.929		SPA	.934	.941
	SLA	.946	.947		SLA	.952	.953
	HSA	.922	.923		HSA	.937	.939
	SA	.942	.942		SA	.953	.953
	AA	.914	.916		AA	.941	.943
Total	HLA	.905	.905	Total	HLA	.945	.947
(Parcel)	CNA	.936	.937	(Parcel)	CNA	.945	.946
	SPA	.920	.923		SPA	.928	.932
	SLA	.935	.936		SLA	.947	.947
	HSA	.935	.935		HSA	.952	.952
	SA	.952	.953		SA	.960	.961
	AA	.937	.941		AA	.952	.956
				uont [
		٦	FXC	ellen			
				arnal			
				in nCV			
				sisterio			
			/ Con			THEUN	IVERSITY OF
				-		KA	NSAS
					L L		

Relationship of the SIS to Intelligence and Adaptive Behavior for Participants with Autism and Intellectual Disability and (Intellectual Disability Only)

			INTELL	IGENCE			
Group	HLA	CNA	SPA	SLA	HSA	the AA	
Total Sample	.45 (.65)	.37 (.58)	.35 (.56)	.31(.46)	.35	cross (.54)	
5-6	.47 (.58)	.44 (.56)	.45 (.47)	.44 (.38)	.4	those (.40)	
7-8	.46 (.61)	.37 (.48)	.36 (.50)	.32 (.39)	.34 60	Daru, ism (.50)	
9-10	.42 (.70)	.34 (.58)	.32 (.58)	.32 (.42)	.32	with Automatical (54)	
11-12	.42 (.68)	.29 (.59)	.34 (.55)	.28 (.48)	.32 (intellection (5)	
13-14	.50 (.66)	.38 (.60)	.29 (.59)	.24 (.50)	.34 (. . ar	id mility had	
15-16	.57 (.65)	.50 (.60)	.35 (.58)	.26 (.48)	.47 (.5)isability	
			ADAPTIVE B	EHAVIOR		correlations	
Group	HLA	CNA	SPA	SLA	HSA	with	
Total Sample	.47 (.67)	.39 (.59)	.37 (.57)	.32 (.47)	.37 (.57)	uidence	
5-6	.47 (.61)	.40 (.61)	.42 (.51)	.41 (.41)	.40 (.51)	intelligentive	
7-8	.40 (.66)	.33 (.51)	.32 (.50)	.29 (.37)	.28 (.51)	and adapt	
9-10	.41 (.71)	.36 (.60)	.34 (.60)	.35 (.42)	.35 (.57)	anahavior	
11-12	.50 (.73)	.38 (.62)	.41 (.60)	.33 (.51)	.40 (.60)	Den	
13-14	.50 (.69)	.40 (.62)	.35 (.61)	.29 (.54)	.38 (.62)	.59) .37 (.63)	
15-16	.59 (.64)	.53 (.56)	.38 (.54)	.26 (.50)	.47 (.57)	.45 (.51) .42 (.52)	_

scores

27		Age Band		Autisr Intelle Disab	n & ctual ility	Intellectu (al Disability Dnly	Effect Size
1	1 11		Construct	M	SE	М	SE	
1	-	5-6	Health and Safety	3.19	.04	2.96	.07	.28
	What I want		Social	3.22	.04	2.84	.07	.45
			Advocacy	3.11	.04	2.90	.07	.26
		7-8	Home Living	2.38	.04	2.62	.06	.30
			Social	3.16	.04	2.87	.07	.36
		9-10	Home Living	2.33	.04	2.60	.05	.34
	1		Social	3.08	.04	2.87	.05	.25
		11-12	Home Living	2.19	.04	2.45	.05	.31
			Social	3.02	.04	2.72	.05	.34
		13-14	Health and Safety	2.98	.04	2.82	.04	.19
			Social	3.01	.04	2.60	.05	.46
			Advocacy	2.99	.04	2.84	.04	.20
		15-16	Community & Neighborhood	2.72	.05	2.50	.05	.27
	ictently		School Participation	2.87	.06	2.63	.06	.27
Cons	social		Health and Safety	2.87	.06	2.57	.06	.33
high	er Suced		Social	2.91	.06	2.37	.07	.56
	port ness		Advocacy	2.98	.05	2.60	.06	.44
SUP	cores							



Section 2E: Social Activities		т	Vne				Fre	anne	nev		Б	ailv	Item Raw Score Sum			
												Jam				
 Maintaining positive relation- ships with others 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Respecting the rights of others	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Maintaining conversation	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Responding to and providing constructive criticism 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Coping with changes in routines and/or transitions across social situations 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Making and keeping friends	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
Communicating with others in social situations	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Respecting others personal space/property 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
Protecting self from exploitation and bullying	0	1	2	3	4	0	1	2	з	4	0	1	2	3	4	
										SUN	1 OF	ITE	M RA	w sc	ORES	
MEA	N RA	TING	FOR	soc	IAL /	ACTI	VITIE	ES = (:	SUM	OFI	ТЕМ	RA	N SC	ORES	5) ÷ 27	

- Also saw differences in some age groups for:
 - Advocacy Activities
 - Youth aged 13-14 and 15-16 with ID-ASD showed HIGHER support needs



Section 2G: Advocacy Activities			Туре	•			Fre	que	ncy		Da	ily Sı	ltem Raw Score Sum			
1. Expressing preferences	0	1	2	з	4	0	1	2	3	4	0	1	2	3	4	
2. Setting personal goals	0	1	2	з	4	0	1	2	3	4	0	1	2	3	4	
3. Taking action and attaining goals	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Making choices and decisions	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Advocating for and assisting others	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Learning and using self-advocacy skills 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
Communicating personal wants and needs	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Participating in educational decision making 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Learning and using problem solv- ing and self-regulation strategies in the home and community 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
										SUM	OF I	TEM	RAW	sco	RES	
MEAN RA	ACTIN	/ITIE	s = (s	UM	OF IT	EM R	AW	SCOF	RES) ÷	- 27						

- Also saw differences in some age groups for:
 - Home Living Activities
 - Youth with ID-ASD tended to generally show LOWER support needs across ages



Section 2A: Home Life Activities			Type	•			Fre	aue	ncv		Da	ilv S	ltem Raw Score Sum			
1. Completing household chores	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Eating	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Washing and keeping self clean	0	1	2	3	4	0	1	2	3	4	0	1	2	з	4	
4. Dressing	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Using the toilet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Sleeping and/or napping	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Keeping track of personal belongings at home 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Keeping self occupied during unstructured time (free time) at home 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Operating electronic devices	0	1	2	3	4	0	1	2	3	4	0	1	2	з	4	
	I	I	I	I	1			I		SUM	OF I	тем	RAW	sco	RES	
MEAN R	ATIN	G FO	R HO)ME I	LIFE	ACTIN	/ITIE	S = (S	SUM	OF IT	EM F	RAW	SCOF	RES) +	÷ 27	
L													•••			

- Youth with ID-ASD aged 15-16 tended to show HIGHER support needs in multiple domains
 - Social
 - Advocacy
 - Community and Neighborhood
 - School Participation
 - Health and Safety



Section 2C: School Participation Activities			Туре	•			Fre	eque	ncy		Da	ily S	ltem Raw Score Sum			
1. Being included in general educa- tion classrooms	0	1	2	3	4	0	1	2	3	4	0	1	2	з	4	
 Participating in activities in common school areas (e.g., play- ground, hallways, cafeteria) 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Participating in co-curricular activities 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Getting to school (includes transportation) 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Moving around within the school and transitioning between activities 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Participating in large-scale test taking activities required by state education systems 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Following classroom and school rules	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Keeping track of personal belongings at school	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Keeping track of schedule at school	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
										SUM	OF I	ТЕМ	RAW	sco	RES	
MEAN RATING FOR SC	ноо	L PA	RTIC	PAT			/ITIE	s = (s	UM	OF IT	EM F	WAS	SCOF	RES) +	÷ 27	

Section 2E: Health and Safety Activities	Туре						Fre	eque	ncy		Da	ily Si	ltem Raw Score Sum			
 Communicating health-related issues and medical problems, including aches and pains 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Maintaining physical fitness	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Maintaining emotional well-being	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Maintaining health and wellness	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Implementing routine first aid when experiencing minor inju- ries such as a bloody nose 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Responding in emergency situations 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Protecting self from physical, verbal, and/or sexual abuse 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
 Avoiding health and safety hazards 	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
										SUM	OF I	TEM	RAW	sco	RES	
MEAN RATING	ORI	HEAL	.TH 8	SAF	ETY /	ACTI	/ITIE	S = (S	SUM (DF IT	EM F	WAS:	SCOF	(ES)	- 24	
													-			17



Implications

- SIS-C is as reliable and valid a tool for children with ID-ASD as it is for those with ID-ONLY
- The same items can be used to measure the seven support need domains across those with ID-ASD and ID-ONLY
- Implications for supports planning for youth with ASD
 - Consider additional exceptional behavioral support needs identified on the SIS-C in planning supports
 - Consider social activities items that might indicate specific support needs that should be addressed
 - May also be unique considerations for 15-16 year old age group as they had significantly higher support needs in five domains
 - Other research has also suggested this may be the case for youth with ID-ONLY



Using the SIS-C to Inform Supports Planning

- Assessment information, in and of itself, does not lead to the effective provision of supports
- Need to take assessment data and translate it into support plans that can be implemented in homes, schools, and communities









Usability of SIS-C

- Teacher Feedback
 - "It's a more authentic assessment than other assessments because it is not just looking at academic performance. It is looking at the child's total performance."
 - "It's easy to say what students can't do. The SIS-C helps you know what they can do with support."
 - "Helps to suggest where to go next in planning activities with a student."
 - "Good for communication with transitions to new teachers and to new schools."



Usability of SIS-C

- Teacher Feedback
 - "Teachers focus on achievement, but teachers need to also consider supports needed for participation, and this scale is helpful in that regard."
 - With the SIS-C, we are not just looking at what students can't do. Because we are looking at supports, we are not looking at what is 'good/not good' about what a student does. Instead, we are looking at what we can do to help support them."
 - "Achievement scores provide a snapshot of what a child has learned, but the SIS-C provides a profile of a child in all the major areas of life."



