



Supporting Transition-Age Youth & Their Families: Research Findings

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Speaker Disclosure Information

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 - PEP-Prentiss Center Autism Speaks ADAMHS Board
 - Music Settlement Support Groups & Listserves
 - Autism Centers & Clinics—UH, MetroHealth, Cleveland Clinic
- **Family Members Who Participated**

Today's Presentation

- Background
- Study Aims
- Methods
- Primary Findings – Service needs & barriers
- Next Steps
- Discussion

Background

- Growing numbers of adolescents & young adults with ASD.
- Many young persons with ASD are at risk for reduced quality of life in adulthood.
- Across chronic illnesses and disabilities, providing care for a family member can result in family caregiver burden and depression.
- Families of adolescents and young adults with ASD face a variety of stressors, especially during the transition years.

Gaps in Knowledge

Note:

“CG” = Family Caregivers

“Youth or Transition-Age Youth” = Adolescents & Young Adults

- Much less research with families of transition-age youth with ASD than with younger children.
- Gaps in Knowledge:
 - How are patterns of service use and service gaps and barriers linked to CG outcomes?
 - What factors are associated with caregiver burden for family CGs?
 - Are CG outcomes shaped by differences in CG demographics and/or characteristics of youth with ASD?

3 Study Aims

#1 – Examine Service Use of Youth with ASD & Their Family CGs

- Service use & experiences
- Facilitators & barriers to service use
- Gaps in needed services

#2 – Assess CG Burden Among These Family CGs

#3 – Examine Impact of CG Stressors, Appraisals, Resources, and Services Gaps & Barriers on Family CG Outcomes

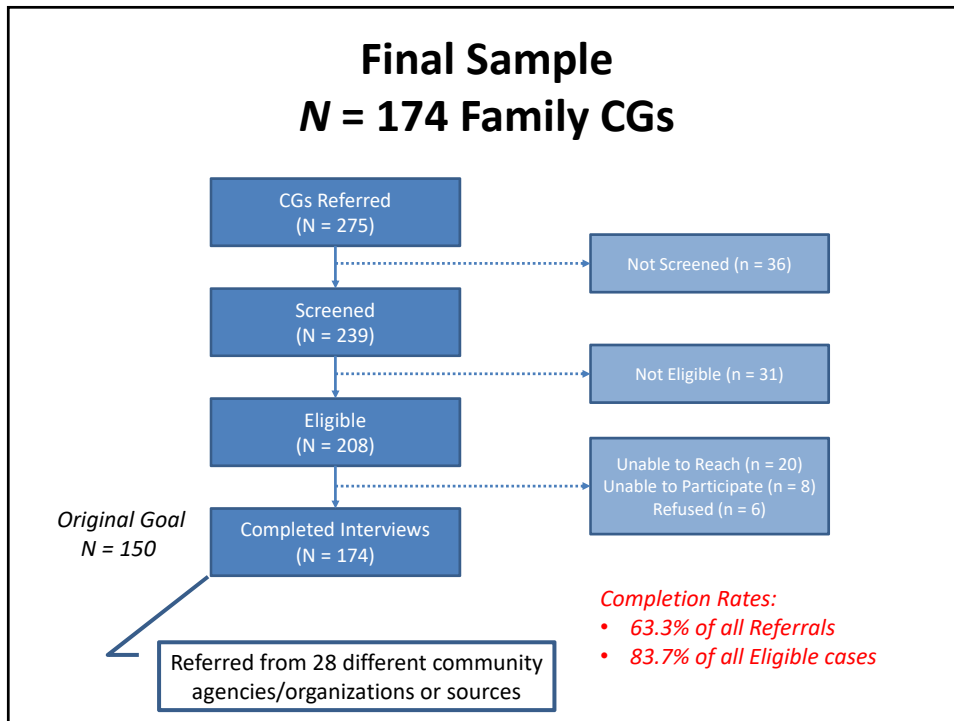
Also within each: Explore potential differences by family CG demographics and characteristics of youth with ASD.

Methods

- **Design:**
 - Cross-sectional survey
 - In-person interviews using trained graduate students
 - \$25 Visa gift card for participation
- **Inclusion Criteria:**
 - Primary family CG (parent, grandparent, guardian) to an adolescent or young adult (age 16 to 30) who had been diagnosed with an Autism Spectrum Disorder
 - No exclusion for multiple diagnoses or living arrangement
- **Recruitment:** NE Ohio ASD service providers, hospitals, self-help groups, schools, conferences & special events, media

Methods

- **Interview Instrument:**
 - Close-ended & open-ended questions
 - Measures used in ASD & other CG research (some adapted)
- **Interviews:**
 - Range: 50-180 min.
 - Average = 95 min.
- **Data Collection:**
 - June 2017 – Nov 2018



Characteristics of Family CGs & Youth with ASD

Caregivers	<i>n</i>	%	Range
Age (yrs.)			
<i>Mean (SD)</i>	54.2	(6.8)	35 - 72
Gender			
Female	159	91.4%	
Male	15	8.6%	
Relationship to ASD Youth			
Parent	168	96.6%	
Other	6	3.4%	
Length of Time as CG (yrs.)			
<i>Mean (SD)</i>	20.3	(4.5)	4 - 30
Race/Ethnicity			
White	139	79.9%	
Black	29	16.7%	
Other or Unknown	6	3.4%	

Caregivers (cont.)	<i>n</i>	%
Married/Partnered	122	70.1%
Cuyahoga County	116	66.7%
Employment Status		
Working FT	73	42.0%
Working PT	45	25.8%
Not working	56	32.2%
Annual Household Income (N = 170)		
< \$30,000	22	13.0%
\$30,000 to \$74,999	51	30.0%
\$75,000 to \$99,999	22	13.0%
\$100,000 to \$150,000	39	22.9%
> \$150,000	36	21.1%

Youth with ASD	<i>n</i>	%	Range
Age			
<i>M (SD)</i>	20.9	(3.7)	16 - 30
Gender			
Female	44	28.0%	
Male	113	72.0%	
Living Arrangement			
In CG's home/apt.	142	81.6%	
In relative or friend's home/apt.	7	4.0%	
Own or shared home/apt.	13	7.5%	
Other supervised setting (e.g., group home, boarding home, dormitory)	12	6.9%	

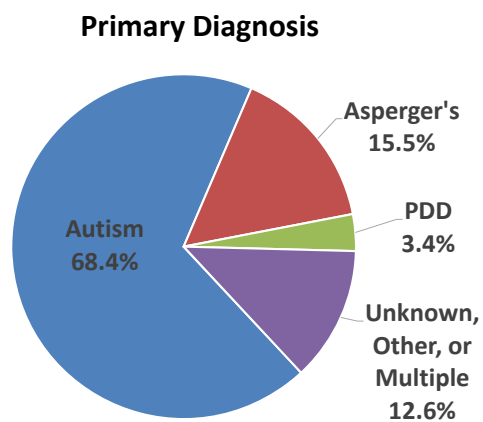
Youth with ASD (cont.)

Asked about 8 Diagnoses:

- Autism
- Asperger's
- Developmental Disability
- Intellectual Disability
- ADD/ADHD
- Learning Disability
- Seizure Disorder (or Epilepsy)
- Mental Health Disorder

Age at ASD diagnosis:

Mean = 6.4 (SD = 5.2)
Median = 4.0



Youth with ASD (cont.)

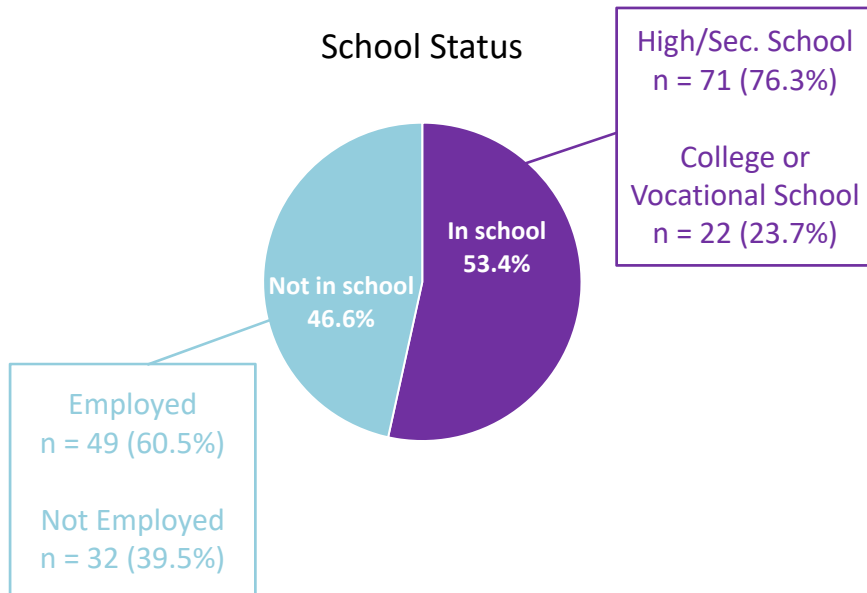
- 93% had multiple diagnoses

Diagnosis (all that apply)	n	%
Autism	150	86.2%
Mental Health (MH) Disorder	106	60.9%
ADD/ADHD	83	47.7%
Developmental Disability	79	45.4%
Learning Disability	58	33.3%
Asperger's	56	32.2%
Intellectual Disability	47	27.0%
Seizure Disorder or Epilepsy	24	13.8%
Other (CP, Tourette's, etc.)	30	17.2%

Common MH Diagnoses:
 Anxiety (76%)
 Depression/Mood (39%)
 OCD (21%)
 Other (21%)
[incl. PTSD, impulse control disorders, Psychotic disorders]

Youth with ASD (cont.)

School Status



Youth with ASD (cont.)

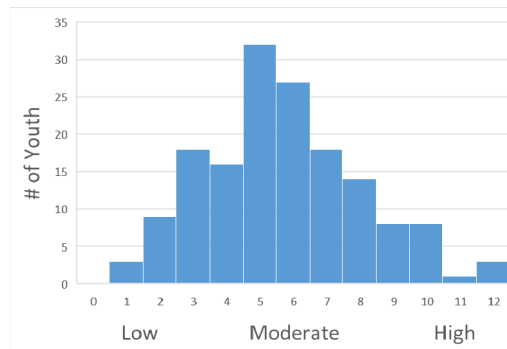
Severity of impairment rated in 3 areas:

Receptive communication Expressive communication Social functioning

Each rated from 0 = None to 4 = Very Severe

Total Score: 0 to 12

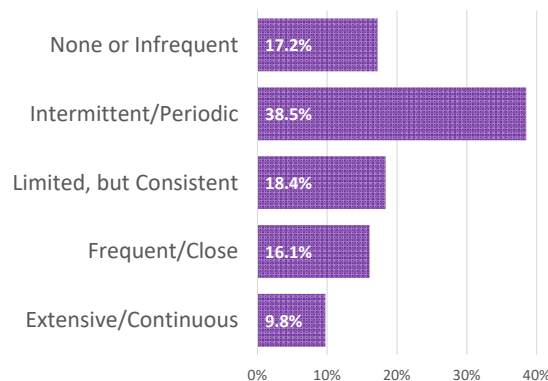
Observed Range: 1 – 12
Mean = 5.7 (SD = 2.4)
Mdn = 6.0

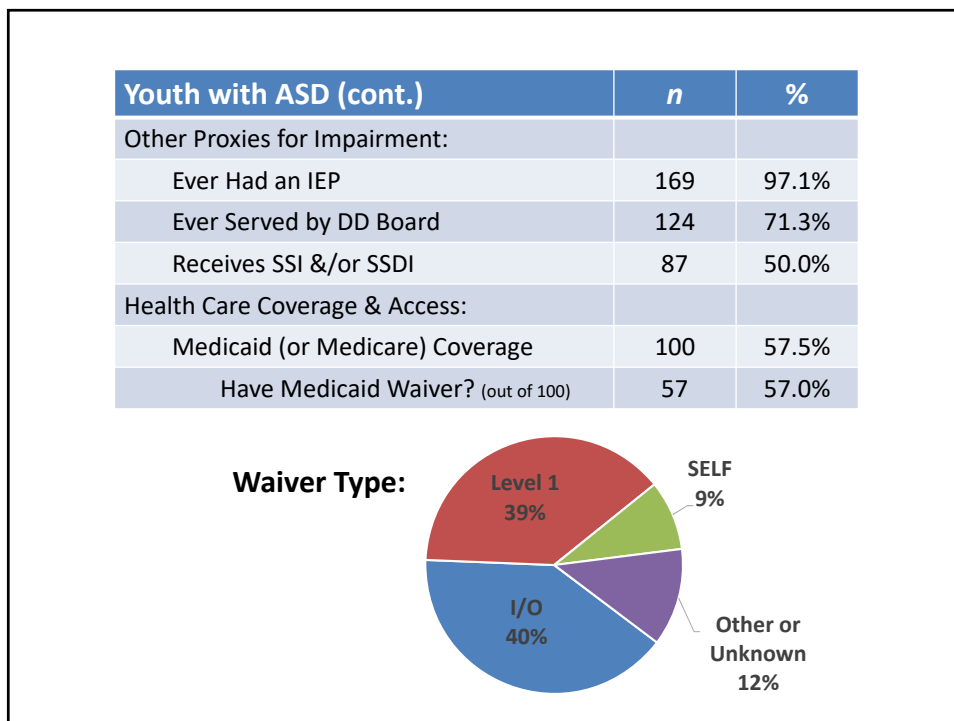
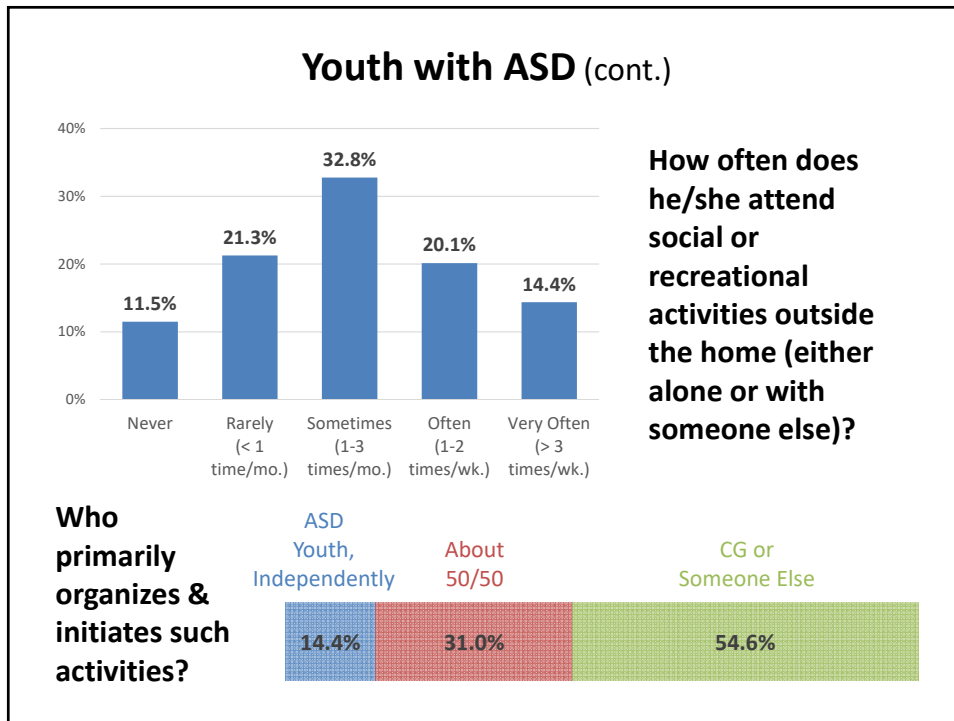


Youth with ASD (cont.)

Support Level

- Scales of Independent Behavior-Revised (Bruininks et al. 1996)
- Combines Adaptive Functioning & Problematic Behaviors
- Level of Support & Supervision Needed (age-based norms)





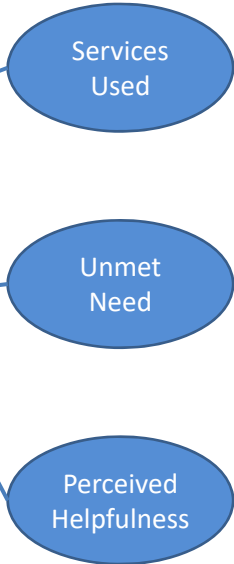
Service Use & Service Needs

Service Use & Service Needs

Youth/family received in the past 6 months....?

Service	Service Use			If Received, How Helpful? 1-Not at all to 5-Very
	Received	Not Received, but Needed	Not Received, but NOT Needed	
Life Skills Education & Training Occupational therapy or other training to improve self-care, daily living skills, and self-advocacy.				

15 types, e.g.:
 Case Management
 Employment
 Medical Care
 Mental Health Care
 Personal Care
 Speech/Language
 Supportive or Compl. Therapies
 Transportation



Service Use

of Services Received (out of 15):

Range = 0 to 15

Mean = 6.1 (SD = 3.2)

Top Services Used	<i>n</i>	%
Medical Care	114	65.5%
Mental Health Care	109	62.6%
Employment Supports	94	54.0%
Case Management	93	53.4%
Educational Supports	88	50.6%

Perceived Helpfulness

Rating Scale:

- 1= Not at all
- 2= Somewhat
- 3= Helpful
- 4= Very Helpful

HIGHEST	Helpful or Very Helpful
Personal Care	96.4%
Transportation	94.8%
Educational Supports	90.9%

Average Rating:

Range = 1.8 to 4.0
Mean = 3.2 (SD = 0.8)

LOWEST	Helpful or Very Helpful
Speech/Language	71.0%
Employment Supports	63.1%
Transition Planning	61.9%

Barriers to Service

- List of 14 possible barriers, e.g.:
 - Cost
 - Location
 - Accessibility
 - Lack of Eligibility
- Rate extent to which each was barrier in past 6 mos:



Barriers to Service (cont.)

Moderate or Major Barriers (out of 14)

Range = 0 to 13

Mean = 4.5 (SD = 3.2)

Top Barriers	Moderate or Major
Lack of information (about svc or how to access)	89 (51.1%)
Not available	77 (44.3%)
Waiting list (for service or for waiver)	76 (43.7%)
Location	69 (38.7%)
Cost	64 (36.8%)
Providers not adequately trained	62 (36.5%)

Unmet Needs

of Services Needed (out of 15):

Range = 0 to 11

Mean = 3.2 (SD = 2.6)

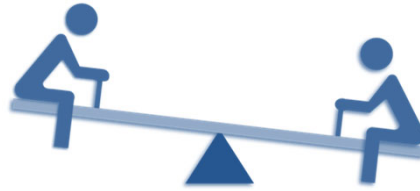
Services Not Received, But Needed	<i>n</i>	%	"Most Important"
Social Supports/ Social Skills Training	75	43.1%	#1
Supportive or Complementary Therapies	62	35.6%	
Transition Planning	58	33.3%	
Life Skills Education & Training	58	33.3%	#3
Employment Supports/ Vocational Training	46	26.4%	#2

Top Barriers to "Most Important" Service

#1 Social Supports/ Social Skills Training	#2 Employment Supports/ Vocational Training	#3 Life Skills Education & Training
Avg # Barriers = 4.8	Avg # Barriers = 4.9	Avg # Barriers = 5.7
Service not available	Lack of information (about svc or how to access)	Waiting list (for service or for waiver)
Lack of information (about svc or how to access)	Service not available	Lack of information (about svc or how to access)
Waiting list (for service or for waiver)	Location of Services	Service not available
Poor Service Quality	Waiting list (for service or for waiver)	Location of Services
Cost	Lack Time for Services	Poor Service Quality
	Poor Service Quality	

Caregiver Well-Being & Service Use

Snapshot of CG Well-Being



- Moderate-to-High Perceived Social Support (Mean = 45.9, SD = 10.7, on 12 – 60 scale)
- 60.2% see “eye-to-eye” with spouse/partner re: youth’s care
- 65% to 74% said caregiving made them feel needed, useful, and good about themselves
- 35.1% displayed clinically significant symptoms of depression
- 28.2% had elevated levels of anxiety
- 64.4% worry “constantly or almost constantly” about the youth’s future

“Biggest” Worry About the Future

*“If something ever happens to me, who
is going to take care of him?
My goal is to outlive him.
More immediately--how will we manage
him when he's done with school?”*



*“Every. Single. Thing.
I worry he won't have basic needs met.
I worry he will be lonely.
I worry he won't be valued or feel fulfilled.
I worry he won't be safe.”*

CG Service Use

- 86.8% aware of CG support groups
 - 51.0% attended in past, 19.9% attend now
 - Mixed ratings of helpfulness
- 24.9% used other family/CG support services in past 6 mos.
 - Educational Conferences
 - Counseling
 - Respite
- 90% rated these as “helpful” or “very helpful”

Barriers to Respite Services

Lack of information
(about svc or how to access)

Waiting list
(for service or for waiver)

Cost

Providers Not Trained

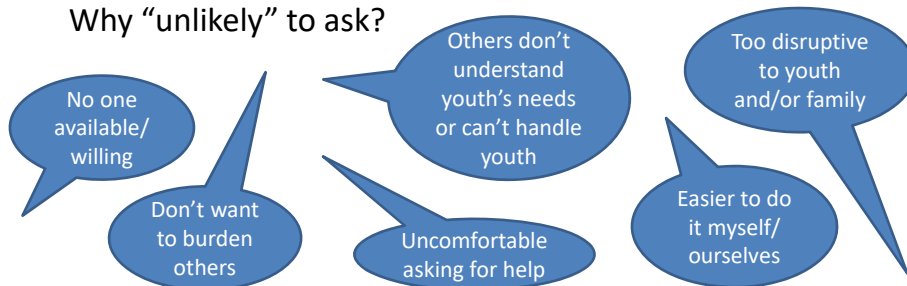
Not Eligible

CG Service Use (cont.)

How likely are you to ask for help/support in caring for youth with ASD?

Very Unlikely	Somewhat Unlikely	Somewhat Likely	Very Likely
44	36	49	45
25.3%	20.7%	28.2%	25.9%

Why “unlikely” to ask?



Advice to Service Providers

CG Advice

- *What advice would you give to service providers about how to improve services to adolescents and adults like _____?*
- Initial Coding: Identified 4 “Themes”
 - Lack of information
 - Interacting with persons with ASD
 - Collaborate with parents
 - Service gaps

Lack of Information

“A lot of things are done piecemeal. [I]t would be good if they could provide a holistic resource pool. Because now I have to find them out little by little through different networks.”

“Let families know what is out there, what is available & how to make it available & better. It's stressful enough raising the child without having to research what I need for transitions.”

Interacting w/Persons with ASD

*“Focus on being people first—
the person and not the disability,
but have an understanding of what the disability is.”*

*“Listen to the person (with ASD);
talk to her as a person; have patience.
Know who you are talking to,
and adjust your interaction accordingly.”*

Collaborate with Parents

*“Collaborate with parents,
be transparent/clear about how
[you] provide services,
be willing to let parents observe before
participating.”*

Service Gaps

*“Have services that are more appropriate
to adults of different ages—
not just ‘18 & over’.”*

*“Don't assume that just because
she is highly intellectually function[ing],
she doesn't need support
and acceptance socially...”*

Service Gaps (cont.)

*“[We] struggle and we fight...
I have to fight for every service.
The answer is always ‘no’ in pursuit of services
[until] I have to
kick someone's a**!”*



Where Do We Go From Here?

Next Steps

- Disseminate Results re: Unmet Needs & Service Barriers and Engage in Discussion with CGs & Community Partners
(here at Milestones Conference & next week at CWRU)
 - Review study findings
 - Discuss implications for development of new or modified programs or services
 - Prioritize action steps
- Secure Funding for New Initiative(s)
 - Partner with community agencies
- Design, Implement, & Test New Programs/Services
- Continue Analyzing Data (e.g., Predictors of CG Well-Being)

Questions & Discussion

Contact Information

Project Co-Directors welcome your feedback and questions:

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