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Parents and Professionals' Autism Information Environment Assessment, Information Needs and Use of Support Services Across the Life-Span of Individuals with Autism [Slides]

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Why study Professionals and Parents' Info Need & Use of Support Services Autism Spectrum Disorders (ASD)?

○ ASD can be diagnosed at an early age and typically the disorder lasts life-long

○ High life-time caring cost ranging from 3.5 million to 5 million per person

○ High maintenance: burden on parents and high demand on professional help

○ No insurance mandate to cover ASD patients, heavy financial burden on families

Proposed Life-Long Coping Model

Information needs and use of support services can be predicted by

○ Perceived Improvement or progress of the individual with autism

○ Length of time since first diagnosis

○ Age of the individual with autism

○ Child symptom severity as moderating variable because it increases stress level and affect coping strategies of parents

Autism information environment

- The consumers' perceived appropriate amount of easy-to-find useful and quality information related to autism available to them.

- Online is the alternative to official sources to consumers. Necessary to focus on the online info environment for autism caregivers and professionals.

- Overall info environment percepton and trust of offline sources can affect the caregivers and professionals' trust and use of online information

Research Method

- An online survey of parents and professionals on the mailing listserv of the Autism Society of Northwest Ohio

- Autism Society of NW Ohio is the largest regional chapter of the Autism Society.

- In NW Ohio, approx 2005 families are affected by autism and 864 professionals work as educators or health care professionals serving people with autism

- Ohio is a state without insurance mandate for people with autism

- An uniform support service setting to focus on the effect of parental factors and life-span factors

Measures

○ **Information Environment Assessment**: Sum of 4-item 5-point Likert scale "Too much information, frustrated in finding useful information, very confusing, quality varies"

○ **Trust in 6 Information Sources**:

A) Govt web sites

B) Non-profit organizations and university web sites

C) social networks sites

D) Commercial web sites

E) Doctors

F) Other parents

○ **Information Needs**: 10 types of information items rated from 1 to 10 from least needed to most needed.

○ **Use of support services/info sources**: never to very frequently (7 are groups and interpersonal sources, 4 are mass media sources)

Hypotheses & Results

1. The more positive the parents see the progress of the ASD individual, the more frequent the person's use of available support resources

○ SUPPORTED (beta= 0.17, p < 0.05)

2. The longer the family member has been diagnosed with ASD, and the older the family member with ASD, the less frequent the parent's use of available support resources

○ SUPPORTED (beta= - .28, p < 05)

3. The longer the family member has been diagnosed with ASD and the older the family member with ASD, the lower the perceived information needs

○ NOT SUPPORTED (beta = 0.05 without demographics, beta=.19, n.s., with demographic variables)

Results

- A total of 250 valid responses (response rate of 15.5%)

- Mirror the composition of the list: 66.4% parents, 33.6% professionals

- Female respondents dominated the sample

- Skewed toward highly educated and high socio-economic status (37.7% parents completed or attened grad school, 30%+ have HH income higher than $90,000.

- Most reported mild to moderate severity of disability

- Average length of diagnosis with autism is 6.8 years (SD=6.8)

Research Questions and Results

1. Do professionals and parents differ in their information environment assessment and their use of and trust in information sources?

○ Both agreed that quality of information varies greatly Parents were more likely to have overall negative assessment than professionals, the only item of significant difference was frustration with finding using information.

○ Parents trusted doctors and other parents more, profesionals trusted government web sites more than parents.

Information Environment Assessment (1 strongly agree, 5 strongly disagree)

	Parents n=152 Mean (SD)	Professionals n=80 Mean (SD)	t	p
Overall assessment*	11.35 (2.6)	12.13 (2.5)	-2.09	0.03
"too much information"	3.98 (.93)	3.99 (.93)	-.057	n.s.
"very confusing"	2.81 (1.01)	2.96 (.97)	-1.12	n.s.
"frustrated with finding useful information"*	2.71(1.03)	3.01 (.93)	-2.19	0.03
"quality varies greatly"	2.03 (.81)	2.12 (.84)	-.72	n.s.
Trust other parents*	2.12 (.85)	2.56 (.80)	-3.78	<0.01
Trust doctor*	2.39 (.94)	2.67 (.64)	-2.64	<0.01
Trust non-profit organization and university web sites	2.41 (.79)	2.37 (.68)	.41	n.s.
Trust government web sites*	3.01 (.88)	2.88 (.74)	2.89	<0.01
Trust social network sites	3.31 (.78)	3.34(.80)	-.26	n.s.
Trust commercial web sites	3.36(.79)	3.51 (.74)	-1.41	n.s.

Note: Missing cases excluded

* significant difference at p < 0.05

2. To what extent do parental factors and life-span factors of the family members of ASD predicts parents' perceived information needs?

- The only significant predictor of information need is INCOME (beta= 0.24. $p < 0.05$), none of the other factors are statistically significant.

3. To what extent do parental factors and life-span factors of the family members of ASD predicts parents' use of support services/information sources?

- The most significant predictor of parents' use of support services/information sources is information need level (beta = 0.32, p < 0.01)

- Income is a significant negative predictor of parents' use of support services (beta= -0.24, p < 0.01): High income respondents didn't see support services meeting their info needs, even though they have higher perceived needs

Predictors of Parents' Use of Support Services/Information Resources

	Model 1 Beta n=132	Model 2 Beta n=105
Online search skills proficiency	-	0.09
Information environment assessment	-	-0.01
Assessment of progress of individual	0.17	0.19
Severity of disability of individual with ASD	0.06	0.13
Age of Family Member with ASD x Year of Diagnosis	0.03	-.20
Information need	-	0.32*
Education	-	0.00
Age	-	0.14
Gender	-	0.01
Income	-	-0.24*
Adjusted R^2	0.09	0.19

* significant difference at $p < 0.05$

Discussion and Conclusion

- Parental factors are more important than life-span factors in predicting information need and use of support services

- Need to stimulate perceived information needs of caregivers

- Support services need to match the specific perceived information needs

- Similar views on the info environment between professionals and parents mean they can work together on the same page in using info sources