How Do Adults with Williams Syndrome Perceive Their Own Levels of Social Vulnerability? Marisa H. Fisher¹ & Emma Lough²

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Introduction

Williams Syndrome (WS)

- Rare genetic neurodevelopmental disorder
- Mild to moderate levels of intellectual disability
- Extreme pro-social drive to engage with others • overly-friendly, trusting, lack social inhibition (Little et al., 2013)
 - disinhibited in approach behavior toward familiar and unfamiliar people
 - (Jarvinen et al., 2013)

 highly vulnerable and at risk of victimization (Fisher et al., 2012; Jawaid et al., 2012; Thurman & Fisher, 2015)

Social Vulnerability in WS

- Experience various forms of victimization
 - Teasing and bullying (Fisher & Lough, under review; Fisher et al., 2013)
 - Theft and giving away money (Fisher et al., 2013)
 - Abuse (Fisher et al., 2013; Rosner et al., 2004)
- •Reasons for increased risk
 - Appear vulnerable in looks and behavior
 - Increased parental independence (on and offline)
- Parent Report
 - Existing research uses parent reports
 - Disparity between parent & self-reports in WS
 - No agreement between self- and parent report

 Adults with WS less accurate in reporting social approach behaviors

 Parent report more closely related to observed social approach behaviors (Fisher et al., 2014)

 Unclear how adults with WS see and report their own levels of social vulnerability

Research Question

- How do adults with WS perceive and report their own levels of social vulnerability?
- Compared to parent reports, do adults with WS provide significantly different responses when asked about their levels of social vulnerability?



Method

Participants

Individuals with Williams Syndrome

- N = 28 (6 female, 22 male)
- Mean age = 27.7 years (SD = 8.4; range 19-51)
- KBIT-2 FSIQ = 69.11 (SD = 15.28)
- 86% lived at home with their parents
- Parents of Individuals with Williams Syndrome
- N = 28 (25 mothers, 3 fathers)
- Mean age = 56.9 years (SD = 7.4)

Measures

- Social Vulnerability Questionnaire (SVQ; **Fisher et al., 2012)**
- 30 items rated on 4- point scale
- (1- not true or never to 4- very true or always)
- Emotional Bullying (score range 5 20)
- Risk Awareness (9 36)
- Social Protection (4 16)
- Vulnerable Appearance (4 16)
- Parental Independence (3 12)
- Credulity (5 20)
- High scores = higher social vulnerability
- Parent version adapted for individual with WS
 - simplified language
 - visual aids for likert scale

No, Never

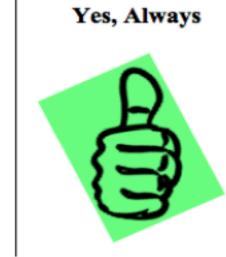
No, Rarely

Yes, Sometimes









Data Analysis

Differences in Ratings of Social Vulnerability

Total Sco

- Emotiona
- **Risk Awa**
- Social Pr
- Vulnerabl
- Parental
- Credulity

Experiences of victimization

Results

• Mann-Whitney U tests to compare non-parametric scores

Parents rated individual with WS as more socially vulnerable overall than individuals rated themselves Significant difference in four out of the six areas of vulnerability Parents reported higher vulnerability levels for risk awareness, social protection, & credulity • Adults with WS reported higher vulnerability to emotional abuse (e.g. being picked on by others, peers

making fun of him/her)

	Parent	Adult	U	Ζ	p
ore	67.32 (8.05)	59.50 (8.57)	193.0	-3.26	.00
al Bullying	7.86 (2.06)	10.79 (3.8)	198.0	-3.2.	.00
areness	16.75 (3.69)	13.46 (2.55)	173.5	-3.61	.00
rotection	9.57 (3.51)	7.46 (3.16)	253.5	-2.28	.02
ole Appearance	12.18 (2.5)	10.61 (2.81)	277.5	-1.89	.06
Independence	7.68 (2.14)	7.82 (2.26)	362.5	-0.49	.62
/	13.46 (2.08)	9.36 (2.9)	102.5	-4.77	.00

• 54% of parents gave an example of when individual with WS had been taken advantage of in the past year • 67% of examples related to money/theft (e.g. being convinced to give money to others) • 27% of examples related to teasing or persuasion (e.g. hassle from work colleagues)

Conclusion

Current study offers novel insight in to how adults with WS view their own vulnerability • Adults with WS to not perceive themselves to be as socially vulnerable as parents perceive them • May lack insight into their own behaviors that could lead to victimization Higher ratings for emotional abuse indicate adults with WS are aware of how others treat them Future Directions for Research Interventions to address self-awareness • Teach to evaluate situations, then teach how to handle such situations More research examining self-report and correspondence between informants

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*References available upon request







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