

# Service Receipt for Individuals with Autism across Canada: Findings from a Canadian National Survey

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# Background

- ASD is a lifelong condition with different concurrent challenges, resulting in diverse need
  - Life stage (Howlin et al. 2009; Gerhardt and Lainer 2011)
  - Clinical need (Brown, Ouellette-Kuntz et al. 2011; Chiri and Warfield 2012)
- Challenging for individuals and families to navigate and access services
- Understanding service use patterns and correlates at key points throughout the lifespan will inform system-level change and policy

# Background

- Having an intellectual disability along with ASD (ASD+ID) is related to higher need
  - Children
    - more unmet need (mental health) compared to ASD-alone (Zablotsky et al., 2015)
  - Youth
    - less independence and social functioning, more maladaptive behaviours, lower educational attainment, worse vocational outlook compared to ASD-alone (Marriage et al, 2009; Shattuck et al., 2007)
  - Adults
    - compared to ID-only, 4x as likely to have behaviour problems (McCarthy 2010)

# Background

- People with ASD+ID also have different service use patterns compared to those with ASD-alone
  - Children
    - 9x more likely to receive services than ASD-alone after adjusting for demographic differences (Zablotsky et al., 2015)
  - Adults
    - 3x more use of day services, but less employment (Taylor and Seltzer, 2010)

# Research questions

- 1) Study 1: In children, how does getting services early relate to unmet service need? Does it differ between those with ASD-only and those with ASD+ID?
- 2) Study 2: In emerging adults, are there differences in service receipt between those with ASD-only and those with ASD+ID?
  - 1) What clinical variables mediate that relationship?
  - 2) How does the context of being in school or having employment affect this relationship?

# Overall methods

- CASDA (Canadian ASD Alliance) National Needs Assessment Survey 2014
  - see Lai & Weiss (2017) for method details
- Online caregiver report
  - All individuals were required to report having received an official diagnosis of an ASD (Autism, Asperger Syndrome, PPD-NOS, PDD, or Autism Spectrum Disorder) by a licensed physician, psychologist, or nurse practitioner, whose scope of practice includes ASD diagnosis to be included.

Overall sample 3185 caregivers reported on 3317 individuals

- 45.8% had ID
- Age range: 2-61 years old

# Overall methods

- List of 23 services and “other” (recoded)
  - Service receipt
    - *Please select any supports or services that [child’s name] has currently or recently received (in the last 6 months), has received in the past only (at least 7 months ago or longer), or has NEVER received.*
  - Unmet need
    - *Which of the following services would you like [child’s name] to have received?*
- Typical day activity (6 choices)
  - *What does [child’s name] do during a typical weekday? Think about the last 4 months.*
- Sociodemographic, clinical need, systemic factors

# Study 1

- 1) In children, how does getting services early relate to unmet service need?
- 2) Does it differ between in those with ASD-only and those with ASD+ID?
- 3) Do systemic and clinical variables mediate an association between early service access and current service need?

Articulating the relationship between having accessed early intervention services and unmet service need through mediating factors can provide a better understanding of how families navigate services and ways to support them better.



# Study 1 methods

- Analysis of children 6-12 years of age
- Participants indicated if they had received early intervention services in the past, our independent variable
  - Early intervention services as reported by caregivers, not necessarily intensive behavioural intervention
- An unmet need score was created by summing the number of services that were never received but would have liked to have received
- Two mediator analyses (ASD-only, ASD+ID)

# Study 1 – sample

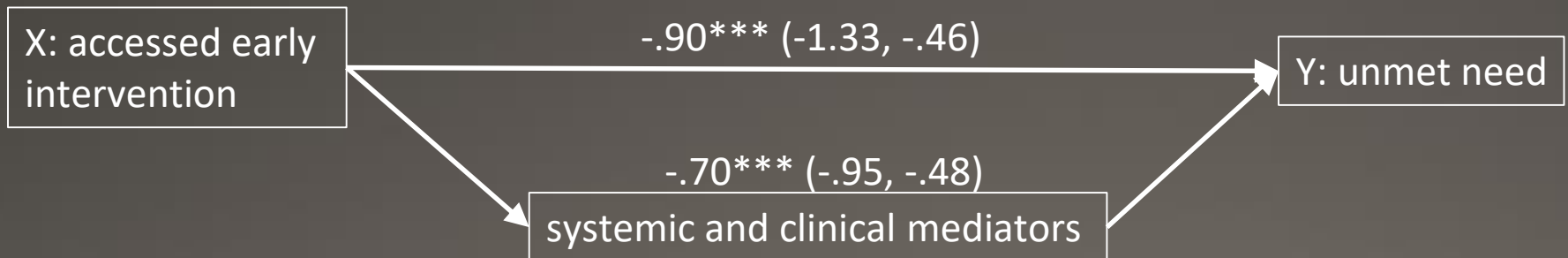
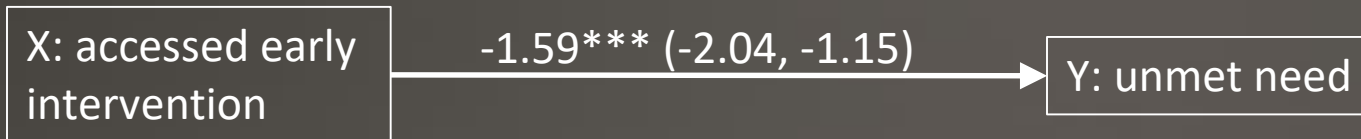
	ASD-only (n=611)	ASD+ID (n=347)	T-statistic or $\chi^2$	p-value
	mean (SD) or %			
<b>Age</b>	9.2 (1.8)	9.3 (1.9)	1.12	0.26
<b>Age of Diagnosis</b>	5.0 (2.3)	4.3 (2.2)	4.2	<.001
<b>Gender (Male)</b>	81.8	83	0.21	0.65
<b>Ethnicity (Caucasian)</b>	84.5	79	4.61	0.03
<b>Caregiver Education Level</b>			6.5	0.09
≤ High School Certificate	7.6	7.4		
College Diploma	44.9	53.6		
Undergraduate Dgr	31.9	25.1		
Graduate/Professional Dgr	15.6	14.5		
<b>Financial Difficulty</b>	24.1	28.8	2.62	0.11
<b>Received Gov't Funding</b>	50.7	68.2	27.68	<.001
<b>Time in Canada (20+ years)</b>	9.8	12.7	0.021	0.65
<b>Community Size</b>			8.01	0.02
Remote or Rural	24.1	20.5		
Suburban	41.5	35.8		
Urban	34.4	43.6		
<b>Current Service Receipt (#)</b>	2.7 (2.1)	3.0 (2.3)	2.26	0.02
<b>Health Status (Poor or Fair)</b>	11.2	7.5	2.36	0.12

# Study 1 – study variables

	ASD-only (n=611)	ASD+ID (n=347)	T-statistic or $\chi^2$	p-value
	mean (SD) or %			
received early intervention	67.9	81.8	21.75	<.001
# of unmet needs	3.7 (2.7)	3.9 (2.5)	1.28	0.2
# of behavioural services	1.5 (1.0)	1.9 (1.0)	5.35	<.001
# of developmental services	2.7 (1.5)	3.4 (1.6)	3.98	<.001
# of general services	2.39 (1.3)	2.43 (1.3)	0.42	0.68
# of behavioural concerns	1.2 (1.3)	1.5 (1.4)	3.33	<.001
# of mental health concerns	1.02 (.8)	0.99 (.8)	0.5	0.61
body function score	1.3 (.9)	1.7 (.9)	6.8	<.001

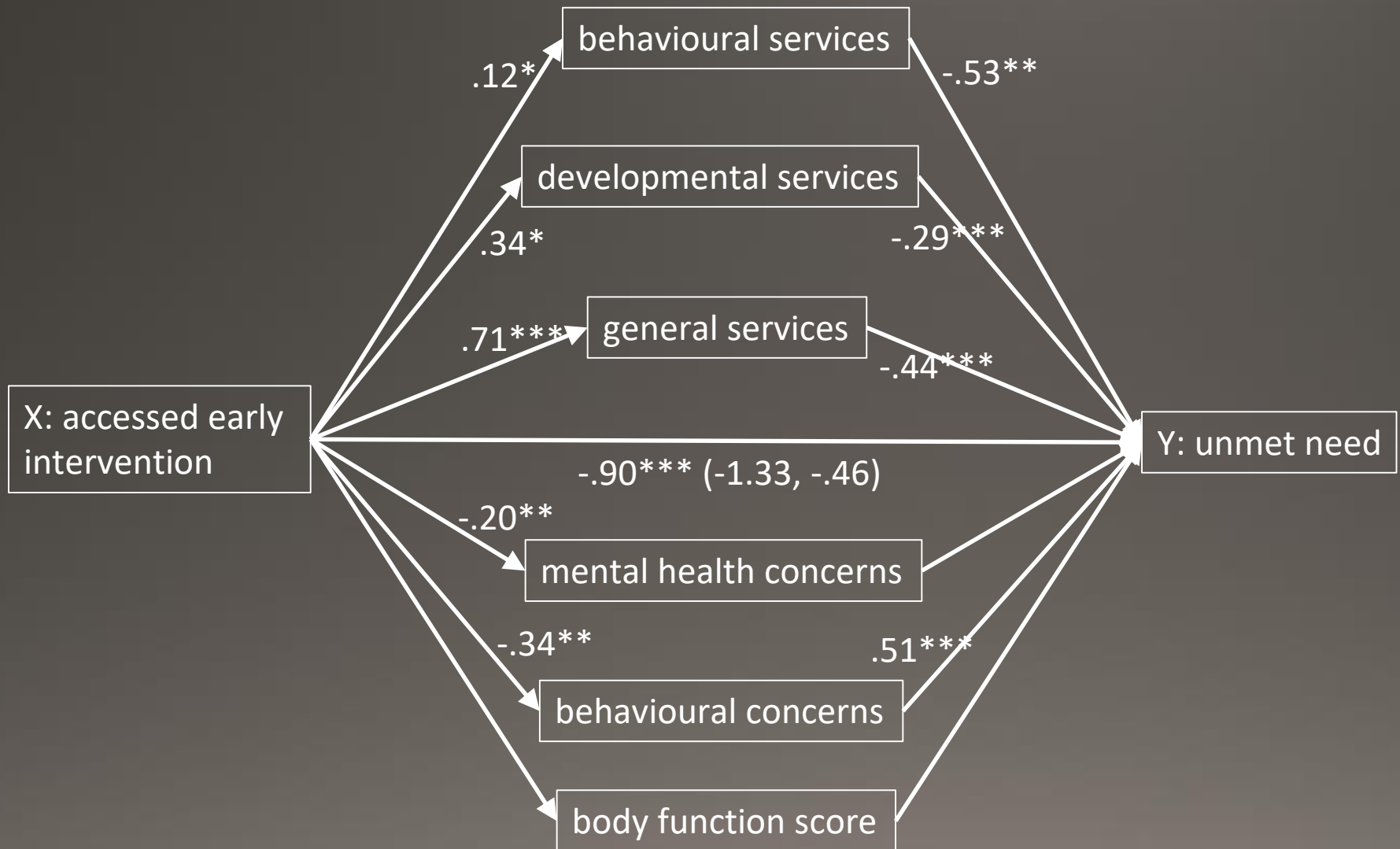
# Study 1 – results: ASD-only

Total effect: 21% of variance



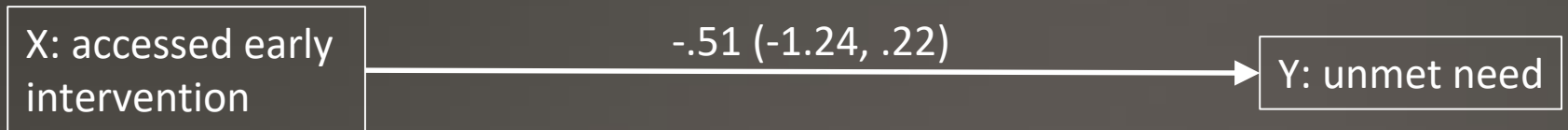
Adjusted for: gov't funding\*\*, barriers\*\*\*, community size, time in Canada\*\*, caregiver education, family finances

# Study 1 – results: ASD-only



# Study 1 – results: ASD+ID

Total effect: 5% of variance



Adjusted for: gov't funding\*\*, barriers\*\*\*, community size, time in Canada\*\*, caregiver education, family finances

# Study 1 – results

## ASD-alone

- Having received early intervention → lower levels of current unmet need
  - adjusted for government funding, barriers to service, and time in Canada
- Mediators or variables that explained the relationship
  - currently receiving more behavioural, developmental and general services
  - having fewer behavioural concerns

## ASD+ID

- Having received early intervention did not relate to current unmet need

# Study 1 – discussion

- ID status plays a role in how services are accessed for children with ASD
  - Those with ID were more likely to have received some form of early intervention, as well as more behavioural and developmental services
  - They were also reported to have greater behavioural concerns and more difficulty with their health as it relates to function
  - For individuals with ASD and no ID, access to early interventions was associated with less unmet need, as a result of greater access to later services and lower clinical need (behavioural concerns)
  - In children with both ASD+ID, this relationship was not present
- Limitations
  - Cross-section correlational study, cannot infer causality or directionality
  - All based on parent report
  - Lack of definitions for services



# Study 2

- Adults have more unmet needs compared to children and adolescents (Turcotte et al., 2016)
- After high school, there is a loss of indirect respite (Power et al., 2009) and a period of life adjustments (Davies and Beamish, 2009), which leads to higher distress in families (McKenzie et al., 2016)
- Emerging adults struggle to remain in meaningful post-secondary situations and obtain services
  - Up to 40% receive no services post-high school (Shattuck 2011)
  - 50% are not enrolled in postsecondary education within 2 years post-high school, and 55% do not have a job within 6 years (Shattuck, 2012)

# Study 2

- Schooling and employment have positive implications for service access
  - associated with having long-term relationships and more independent living arrangements (Eaves and Ho, 2008; Howlin, 2005; Kobayashi, 1992; Cai 2016), as well as better service access (Taylor and Seltzer, 2011)
  - especially for those that may be socially and economically disadvantaged, school-based services may be a key channel to meet needs (Narendorf 2011)

# Study 2

- 1) In emerging adults with ASD (18-25 years old), how does having an intellectual disability (ID) relate to service receipt?
- 2) What clinical variables mediate that relationship?
- 3) How does the context of being in school or having employment affect this relationship?

# Study 2 – methods

- emerging adults (ages 18-25) with ASD-only or ASD+ID
  - sociodemographic data (including current schooling/employment status)
  - clinical need (including mental health, behavioural problems, overall function)
  - systemic variables related to service receipt (including barriers to services, caregiver-directed services)
- current service use – sum of services used in the last 6 months

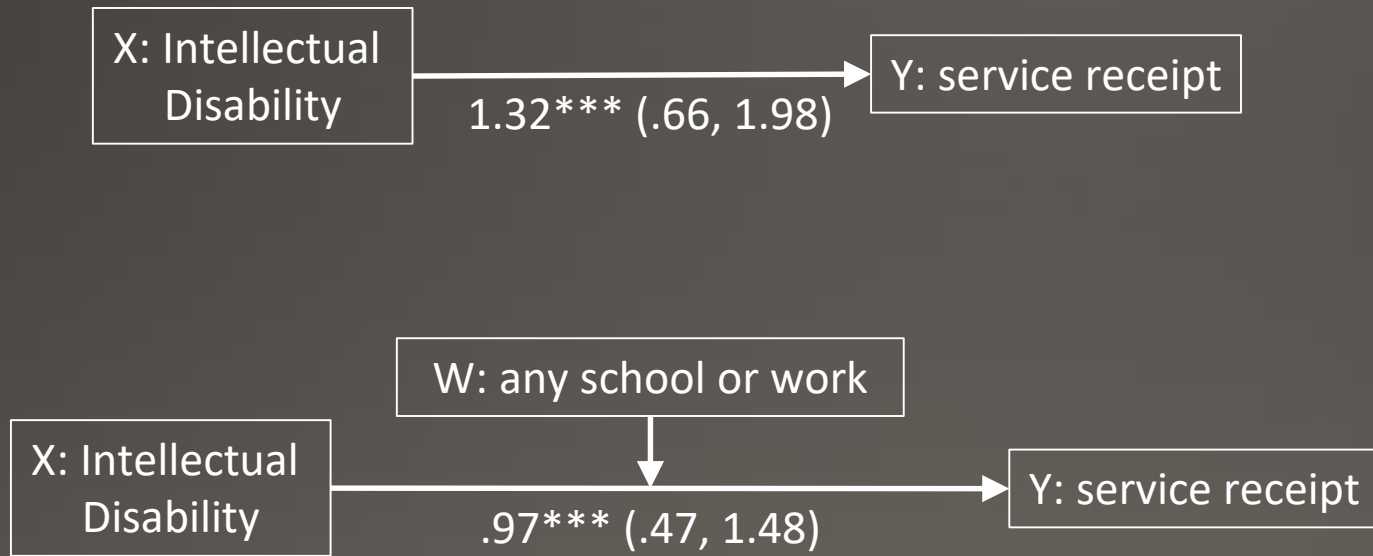
# Study 2 – sample

	ASD-only (n=251)	ASD+ID (n=333)	T-statistic or $\chi^2$	p- value
	mean (SD) or %			
<b>Age</b>	20.5 (2.2)	20.7 (2.1)	0.87	.39
<b>Gender (Male)</b>	83.3	79.3	1.48	.22
<b>Ethnicity (Caucasian)</b>	87.6	88.6	0.12	.73
<b>Caregiver Education Level</b>			1.55	.67
≤ High School Certificate	7.1	9		
College Diploma	47.9	45.8		
Undergraduate Dgr	23.3	26		
Graduate/Professional Dgr	21.7	19.2		
<b>Time in Canada (20+ years)</b>	97.2	96.7	0.12	.73
<b>Community Size</b>			5.07	.08
Remote or Rural	25.3	19.6		
Suburban	41.0	38.1		
Urban	33.7	42.3		
<b>Health Status (Poor or Fair)</b>	11.2	7.5	2.36	.12

# Study 2 – mediators

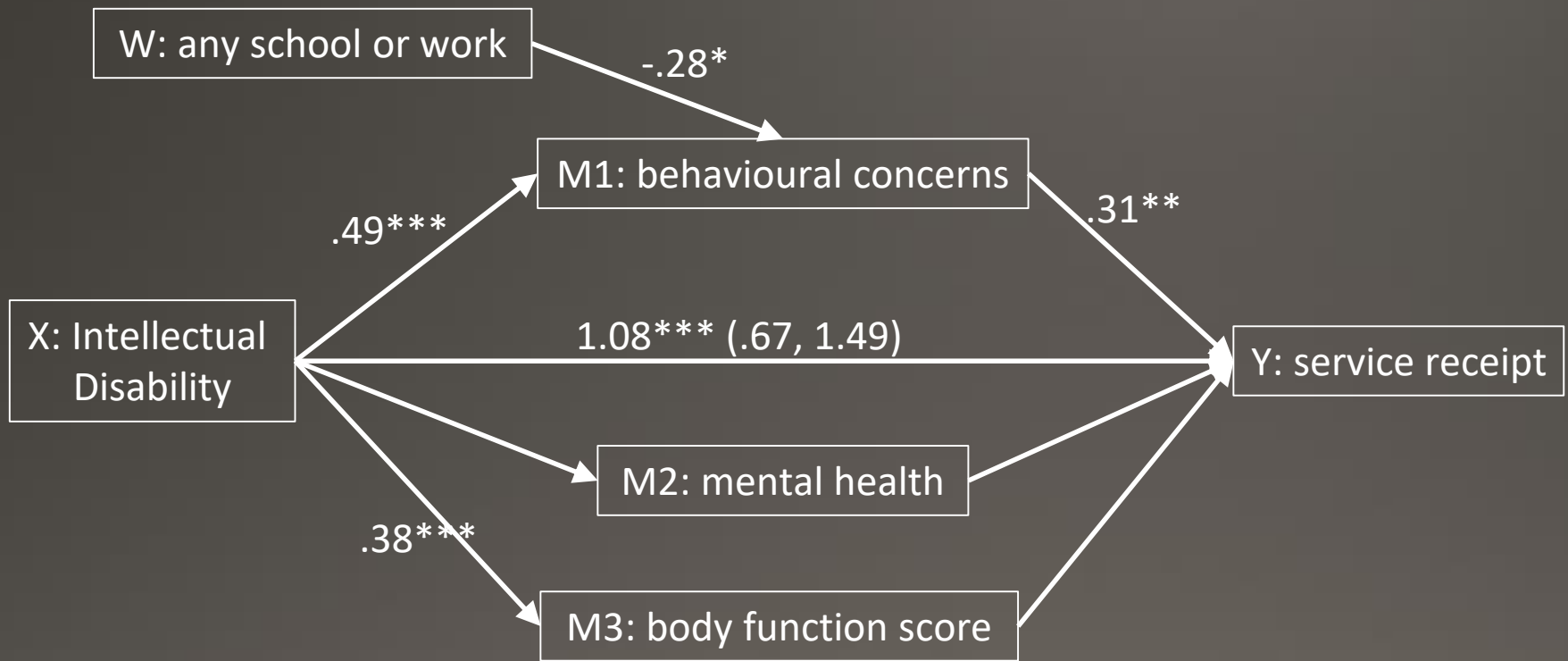
	ASD-only (n=251)	ASD+ID (n=333)	T-statistic or $\chi^2$	p-value
	mean (SD) or %			
# of services received	1.82 (1.9)	3.28 (2.7)	7.67	<.001
# of behavioural concerns	0.79 (1.1)	1.43 (1.6)	5.6	<.001
# of mental health concerns	1.51 (1.1)	1.47 (1)	0.45	.66
body function score	1.32 (1)	1.69 (0.9)	4.99	<.001
Currently in school or job	74.1	64.6	6.05	.01

# Study 2 – results



Adjusted for: age, gov't  
funding, ethnicity

# Study 2 – results



Conditional indirect effect: behavioural concerns

- No school/work = .12 (-.02, .42)
- School/work = .17 (.05, .35)



# Study 2 – discussion

- emerging adults with ASD+ID have more behavioural concerns and body function impairments than ASD-only
  - behavioural concerns partially explain why those with ASD+ID receive more services
- being in school/employed moderates (decreases service receipt) through having less behavioural problems
- for those not in school or those unemployed, behavioural concerns do not explain increased service receipt for those with ASD+ID

# Conclusions

- Having ID changes how both children and emerging adults with ASD interact with the service system
  - Children with ASD-only who receive early intervention may not only benefit clinically, but receive other services later on that reduce unmet need
  - The number of behavioural concerns of emerging adults with ASD+ID drive their increase in service use, but only when they are in school or employed
- Understanding the patterns of service use could decrease caregivers stress through more effective allocation of resources and policy

# Acknowledgements

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# Thank you for your attention!

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