

Supporting the Individual Differences of Autism: Respecting Neurodiversity

Steven Kapp



EGENIS, THE CENTRE FOR THE STUDY OF LIFE SCIENCES



Preview of talk

- Introduction to social model, neurodiversity movement
- Individual differences – strengths, eye contact
- Helpful support vs. abuse marketed as treatment
- Social support's contribution to quality of life

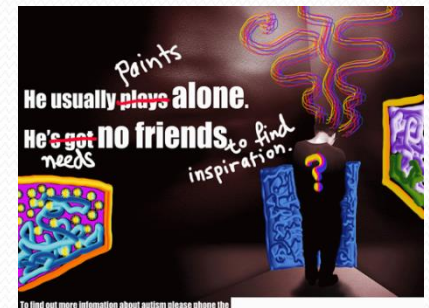
Disability rights movement

- Social contribution to/construction of disability
- Civil rights model – not medical model
- Self-advocacy: “Nothing About Us Without Us”
- Focus on self-determination and quality of life: building independence, inclusion, productivity through rights and support
- For respect, against personal tragedy narrative



Neurodiversity movement

- Autism: complex, pervasive; part of personality
 - Often identity-first, non-medicalized language
- Autism: natural, on spectrum of human diversity
- Focus on rights, access, opportunities -> quality of life
- For acceptance; against prevention and normalization



What works for whom and why?

- Little knowledge about what “works” for whom and why
 - Common knowledge that no intervention works for all
- Little evidence treatment improves long-term “outcomes”
- Little ability to predict “outcomes” at individual level
- Little known for whom, how autism diagnoses tend to help

**ASAN Statement on Fein Study on
Autism and “Recovery”**



**Opportunities and Perils of Extremely Early
“Autism” Intervention**



Strengths of autism

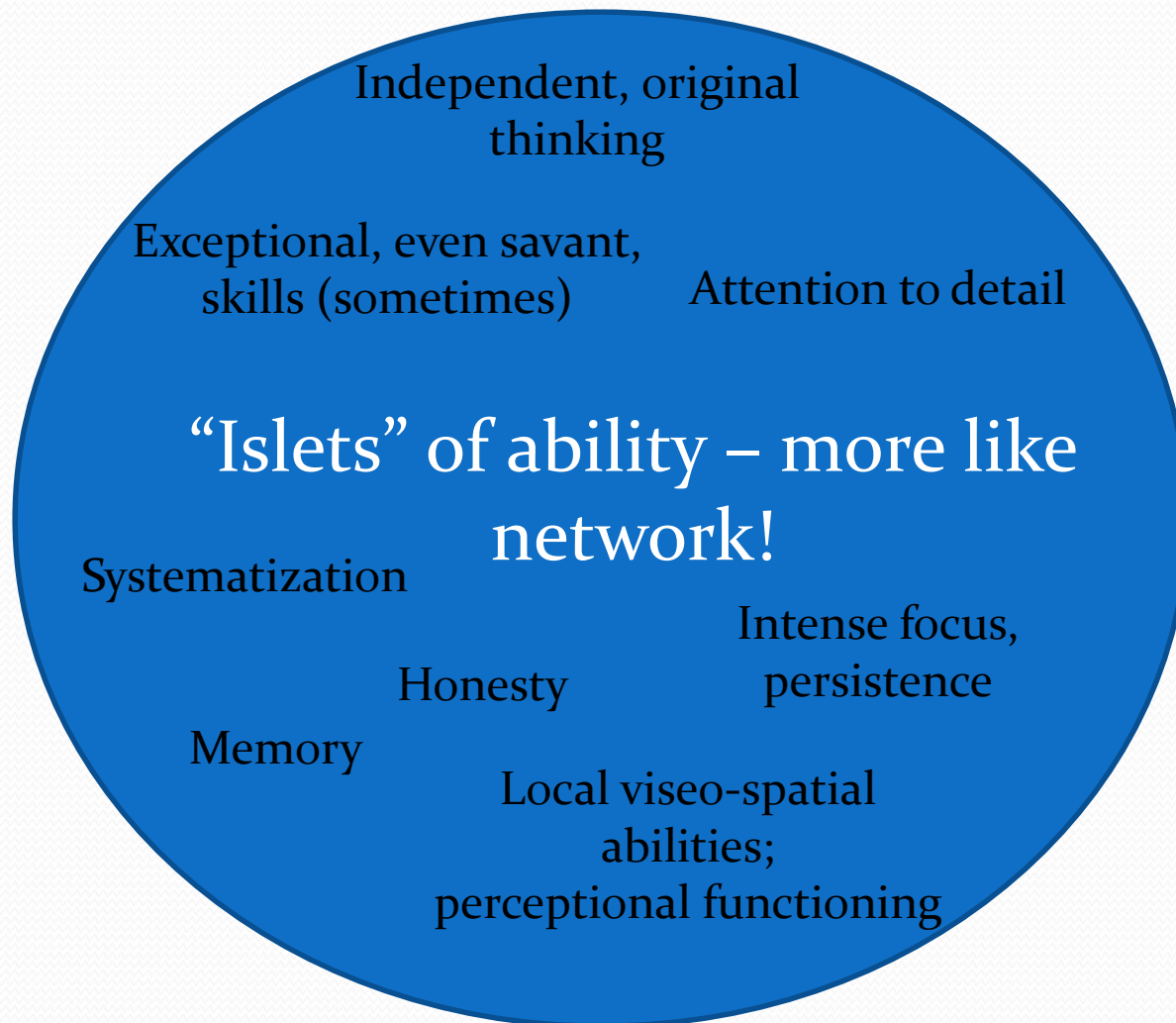
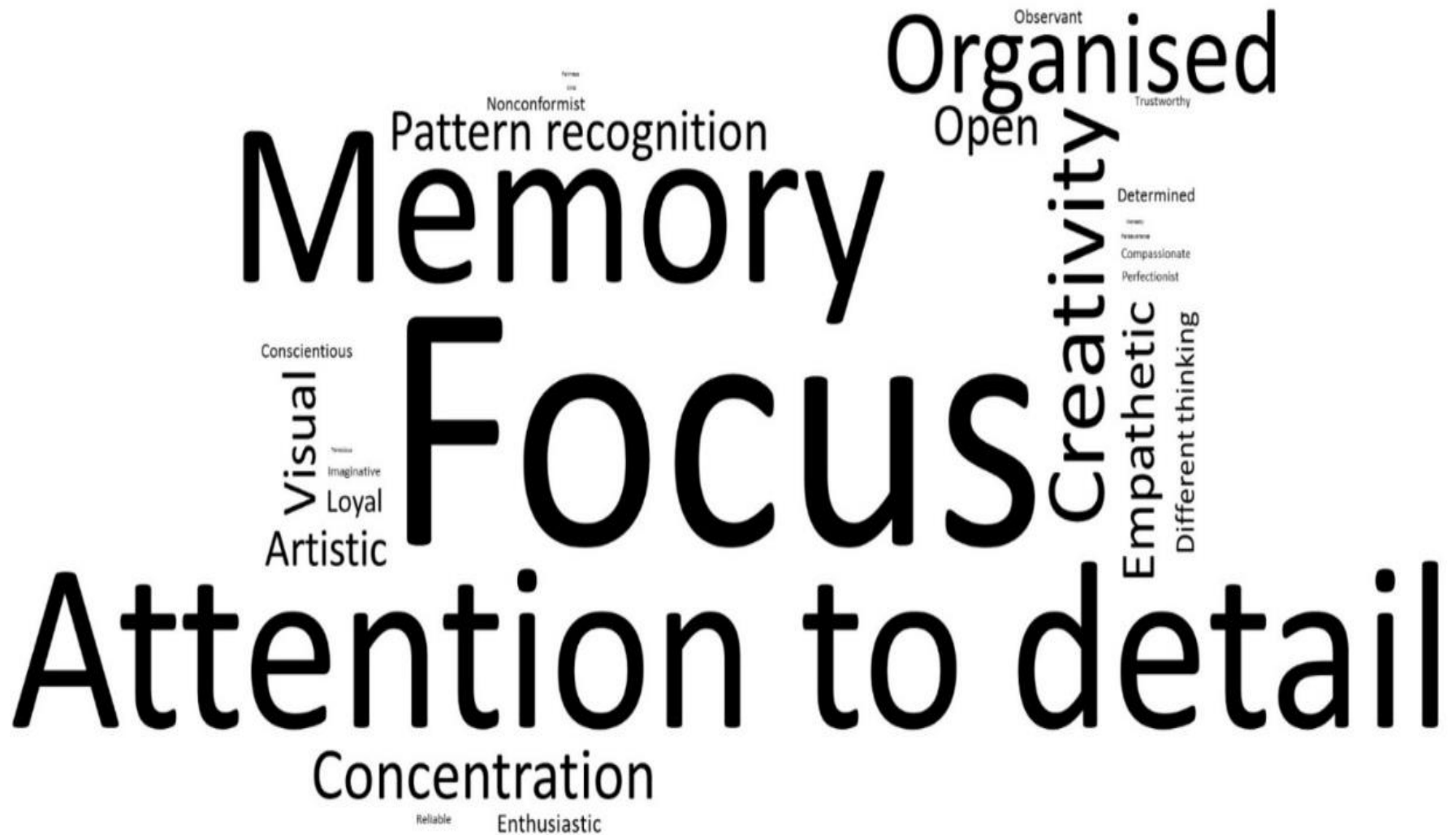


Figure 1: Word cloud of advantageous traits described by participants



SOCIAL WORLD

ADVANTAGE

- Completes tasks to high standard
- Improves communication
- Better relationships

DISADVANTAGE

- Lost sleep
- Poor physical or mental health
- Poor relationships

CONTEXT

MODERATORS

- Extent
- Perspective
- Agency

INDIVIDUAL BEHAVIOUR

1

2

3

NEUROLOGICAL

4

NEUROLOGICAL DIFFERENCE

- Processing
- Perceptual/sensory
- Personality traits

TRAITS

E.g.

- Memory
- Attention to detail
- Focus

COGNITIVE

○ = themes

- 

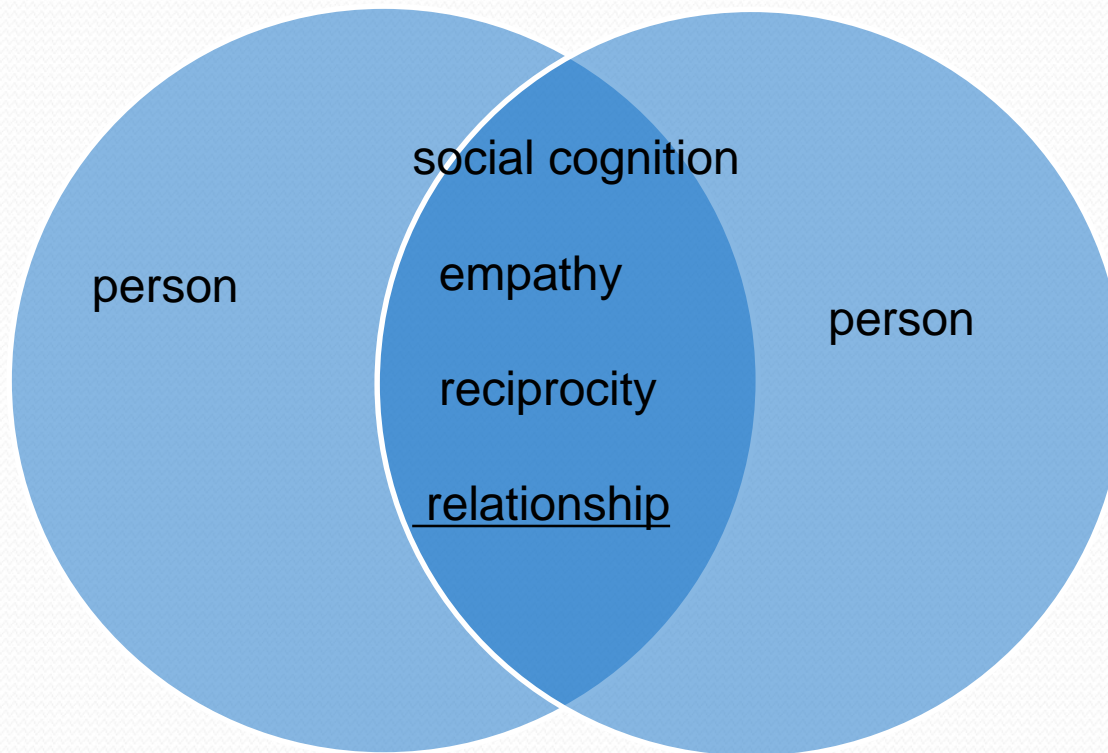
Reasons for atypical eye contact

- Enhanced perception
- Difficulty watching and listening at the same time
- Intense threat detection
- Reduced oculomotor (eye movement) control
- Sticky attention
- Prosopagnosia (faceblindness)
- Culture!

Note: eye contact is not necessarily atypical



Social interaction



Inclusion and support

- Aides focus on whole class
- Preparation for work in and through school
- Communication technology such as iPad and its apps
- Positive parenting
- Intervention programs that value autistic culture

Helpful support

- Positively seek useful skills/development but
 - Not normalization, compliance
- Ways to build communication
 - Understand and accept the person; become in sync
 - Speak in the person's language, follow person's lead, imitate
 - Do not talk, touch too much, but do gesture
 - Consider incorporating the arts (music, drama)
 - Augmentative and alternative communication



Augmentative and Alternative Communication

other ways to communicate besides speech

Sensory-sensitive support

- Lipreading to interact
- Slowing down the presentation of facial expressions
- Colour filters for communication
- Looking at own body to learn movements
- Responsive rather than directive caregiving
- Song, music
- Others' imitation of autistic people
- Augmentative & alternative communication (e.g. iPad)

Figure 1: Stimming is a self-managing process

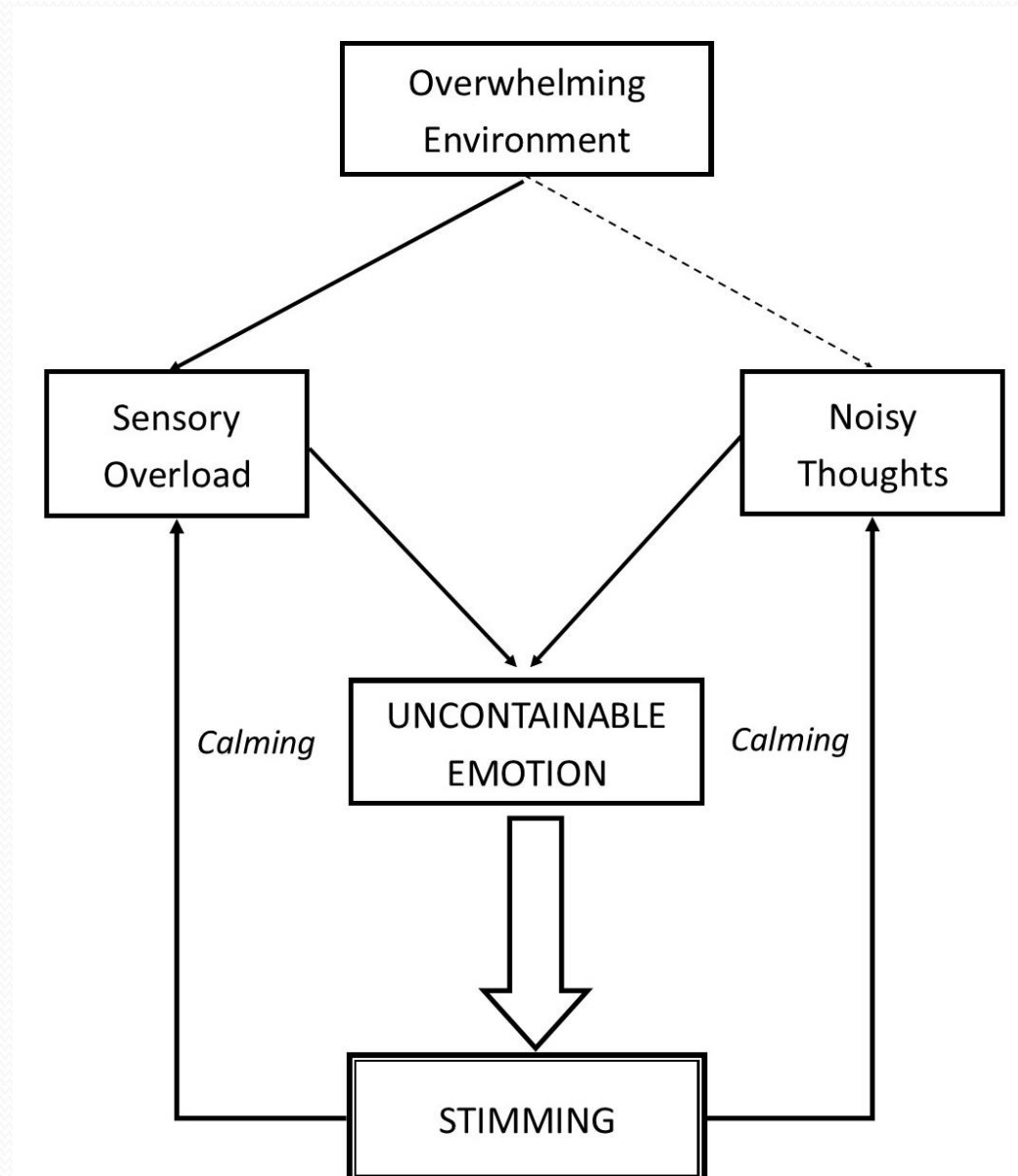
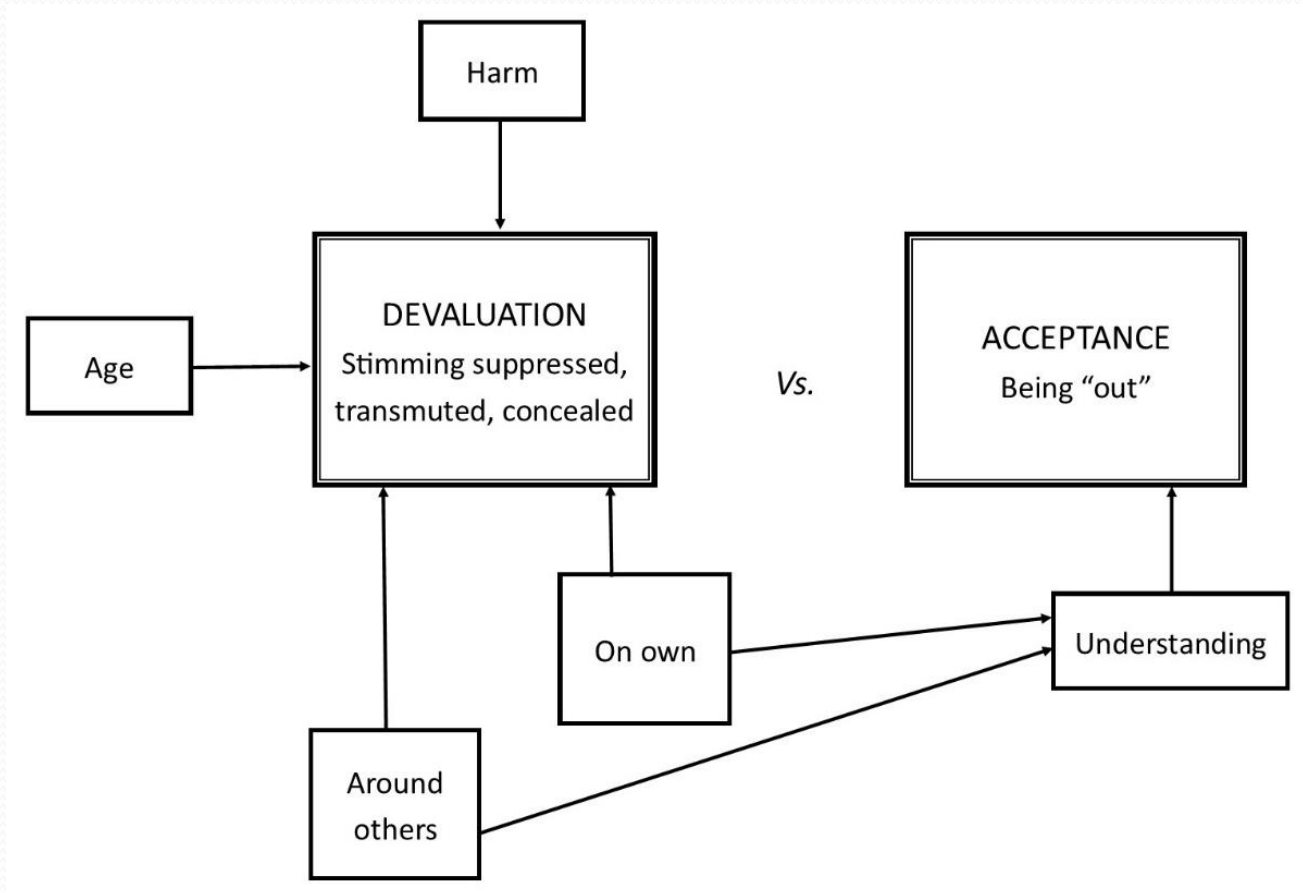
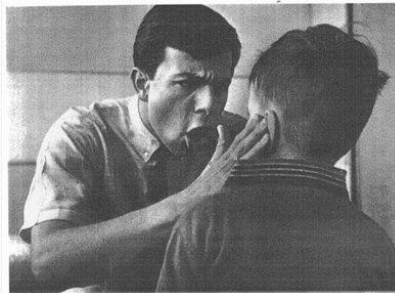


Figure 2: (De)stigmatisation of stimming (rejection and acceptance)



Attempts to end stimming

- 1965: “Screams, Slaps, and Love”, *LIFE Magazine*
- 1987: 47% of autistics “indistinguishable from peers”
- Present: Judge Rotenberg Center in U.S. still shocks



Trying to end stimming is “abuse”

- “...but to me it was abuse, because stopping those children stimming when they're trying to calm themselves down or cope with a situation ... because even if they manage all the environment around them, there might be situations that they find stressful, and if they haven't got the ability to calm them down, then they could be relying on other people for the rest of their lives or have a breakdown”



Social Support, Well-Being, and Quality of Life Among Individuals on the Autism Spectrum



Free copy available
at
[blogs.exeter.ac.uk/
exploringdiagnosis
/publications](http://blogs.exeter.ac.uk/exploringdiagnosis/publications)

Introduction

- Autism mainly diagnosed by social communication
- Social interaction occurs *between* people
- Dynamics with others hugely affect autistics' lives
- Talk highlights roles of social support and subjective well-being for autistics' quality of life (QoL)
 - Objective QoL: adaptive functioning in major domains
 - Subjective QoL: personal judgment, feelings about life

Parental support:

Language acquisition

- Responsive parenting especially helps autistic children performing at lower levels to develop language¹⁻¹¹

Autism acceptance

- Parental autism acceptance¹²⁻¹⁵ and positive emotions toward child¹⁶ are *not* associated with child symptoms, disability
- Parental autism acceptance *is* associated with better parent-child reciprocity^{17,18} and relationship^{19,20}

School support:

Educational inclusion

- Inclusive learning settings are associated with better functioning for autistics²¹⁻²³, especially those with delays²²

Social (peer) inclusion

- Autistic youth with *more* social attempts and skills tend to suffer more victimization, stigma, distress²⁴⁻²⁷

Systemic support in adulthood

- Among autistic young adults transition from secondary school tends to produce relatively more struggle for those *without* intellectual disability²⁸⁻³⁰
 - More often lose services³¹
- Services³² and employment³³ tend to improve functioning

Subjective well-being

- Children and adults who perform or are perceived as higher skilled or functioning tend to judge their autism as more severe and endorse more anxiety and depression³⁴⁻³⁹
- Pattern may relate to victimization and mistreatment
 - Autistic adults report quality of life may relate to social support, not autistic traits⁴⁰
 - Similarly, social support tends to weigh more heavily in self- than parent report of autistic adults' quality of life⁴¹

Implications

- No direct relationship between autism symptoms and functioning
 - Importance of social context
 - (Some) autism symptoms can have neutral or positive effects on well-being
- Importance of understanding and sensitive responding to autistic people, acceptance, inclusion

References

- 1 Baker, J. K., Messinger, D. S., Lyons, K. K., & Grantz, C. J. (2010). A pilot study of maternal sensitivity in the context of emergent autism. *Journal of Autism and Developmental Disorders*, 40(8), 988-999.
- 2 Bang, J., & Nadig, A. (2015). Learning language in autism: Maternal linguistic input contributes to later vocabulary. *Autism Research*, 8(2), 214-223.
- 3 Dimitrova, N., Özçalışkan, Ş., & Adamson, L. B. (2016). Parents' translations of child gesture facilitate word learning in children with autism, Down syndrome and typical development. *Journal of Autism and Developmental Disorders*, 46(1), 221-231.
- 4 Haebig, E., McDuffie, A., & Weismer, S. E. (2013a). Brief report: Parent verbal responsiveness and language development in toddlers on the autism spectrum. *Journal of Autism and Developmental Disorders*, 43(9), 2218-2227.
- 5 Haebig, E., McDuffie, A., & Weismer, S. E. (2013b). The contribution of two categories of parent verbal responsiveness to later language for toddlers and preschoolers on the autism spectrum. *American Journal of Speech-Language Pathology*, 22(1), 57-70.
- 6 Kasari, C., Paparella, T., Freeman, S., & Jahromi, L. B. (2008). Language outcome in autism: randomized comparison of joint attention and play interventions. *Journal of Consulting and Clinical Psychology*, 76(1), 125-137.

References (continued)

- 7 McDuffie, A., & Yoder, P. (2010). Types of parent verbal responsiveness that predict language in young children with autism spectrum disorder. *Journal of Speech, Language, and Hearing Research*, 53(4), 1026-1039.
- 8 Naigles, L. R. (2013, November). Input and language development in children with autism. In *Seminars in Speech and Language* (Vol. 34, No. 4, pp. 237-248). Thieme Medical Publishers.
- 9 Sandbank, M., & Yoder, P. (2016). The association between parental mean length of utterance and language outcomes in children with disabilities: A correlational meta-analysis. *American Journal of Speech-Language Pathology*, 1-12.
- 10 Siller, M., Hutman, T., & Sigman, M. (2013). A parent-mediated intervention to increase responsive parental behaviors and child communication in children with ASD: a randomized clinical trial. *Journal of autism and developmental disorders*, 43(3), 540-555.
- 11 Siller, M., & Sigman, M. (2008). Modeling longitudinal change in the language abilities of children with autism: parent behaviors and child characteristics as predictors of change. *Developmental psychology*, 44(6), 1691-1704.
- 12 Hutman, T., Siller, M., & Sigman, M. (2009). Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play. *Journal of Child Psychology and Psychiatry*, 50(10), 1255-1263.

References (continued)

- 13 Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the diagnosis among parents of children with autism spectrum disorder: Associations with child and parent characteristics. *Journal of autism and developmental disorders*, 40(1), 89-99.
- 14 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development*, 80(2), 519-527.
- 15 Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*, 12(5), 575-594.
- 16 Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, 52, 91-99.
- 17 Hutman, T., Siller, M., & Sigman, M. (2009). Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play. *Journal of Child Psychology and Psychiatry*, 50(10), 1255-1263.
- 18 Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*, 12(5), 575-594.

References (continued)

- 19 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between maternal insightfulness/resolution and child-mother attachment: The case of children with Autism Spectrum Disorder. *Attachment & Human Development*, 14(6), 567-584.
- 20 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development*, 80(2), 519-527.
- 21 Kurth, J. A., & Mastergeorge, A. M. (2010a). Academic and cognitive profiles of students with autism: implications for classroom practice and placement. *International Journal of Special Education*, 25(2), 8-14.
- 22 Nahmias, A. S., Kase, C., & Mandell, D. S. (2014). Comparing cognitive outcomes among children with autism spectrum disorders receiving community-based early intervention in one of three placements. *Autism*, 18(3), 311-320.
- 23 Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Contextual factors predict patterns of change in functioning over 10 years among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(1), 176-189.
- 24 Jones, A. P., & Frederickson, N. (2010). Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream school. *Journal of Autism and Developmental Disorders*, 40(9), 1094-1103.

References (continued)

- 25 Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders*, 6(3), 1126-1134.
- 26 Shtayermman, O. (2009). An exploratory study of the stigma associated with a diagnosis of Asperger's syndrome: The mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. *Journal of Human Behavior in the Social Environment*, 19(3), 298-313.
- 27 Shtayermman, O. (2007). Peer victimization in adolescents and young adults diagnosed with Asperger's Syndrome: a link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing*, 30(3), 87-107.
- 28 Taylor, J. L., & Seltzer, M. M. (2011a). Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(10), 1397-1410.
- 29 Taylor, J. L., & Seltzer, M. M. (2011b). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566-574.

References (continued)

- 30 Taylor, J. L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40(12), 1431-1446.
- 31 Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine*, 165(2), 141-146.
- 32 Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Developmental Psychology*, 50(3), 699-708.
- 33 Taylor, J. L., Smith, L. E., & Mailick, M. R. (2014). Engagement in vocational activities promotes behavioral development for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(6), 1447-1460.
- 34 Bishop, S. L., & Seltzer, M. M. (2012). Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(11), 2354-2363.
- 35 Capps, L., Sigman, M., & Yirmiya, N. (1995). Self-competence and emotional understanding in high-functioning children with autism. *Development and Psychopathology*, 7(01), 137-149.
- 36 Lai, M. C., Lombardo, M. V., Pasco, G., Ruigrok, A. N., Wheelwright, S. J., Sadek, S. A., ... & MRC AIMS Consortium. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS one*, 6(6), e20835

References (continued)

- 37 Mazurek, M. O., & Kanne, S. M. (2010). Friendship and internalizing symptoms among children and adolescents with ASD. *Journal of Autism and Developmental Disorders*, 40(12), 1512-1520.
- 38 Sterling, L., Dawson, G., Estes, A., & Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38(6), 1011-1018.
- 39 Vickerstaff, S., Heriot, S., Wong, M., Lopes, A., & Dossetor, D. (2007). Intellectual ability, self-perceived social competence, and depressive symptomatology in children with high-functioning autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 37(9), 1647-1664.
- 40 Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10(5), 511-524.
- 41 Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders*, 46(4), 1368-1378.

Acknowledgments

- Seminar team for invitation and funding
- Ginny Russell and the Exploring Diagnosis team at the University of Exeter for further funding and comments
- The Wellcome Trust for funding Exploring Diagnosis
- Healthcare Transitions Research Network for inviting me to contribute article
- Connie Kasari and the Health Resources and Services Administration of the U.S. Department of Health and Human Services for funding time on the article

Q & A

- Questions?
- Comments?
- Suggestions?



For further contact: **s.k.kapp@exeter.ac.uk**