

Growing older with autism, preventing loneliness and working together

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What is loneliness?

- A negative emotional state related to the perception of unfulfilled intimate and social needs (Peplau & Perlman, 1982)
- Two types of loneliness (Weiss, 1973):
 - Social loneliness
 - Social isolation, lack of social integration and embeddedness
 - Emotional loneliness
 - Absence of a reliable attachment figure, such as a partner



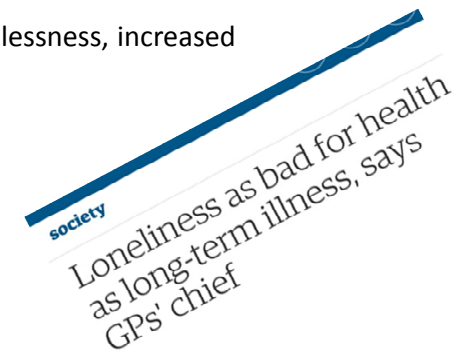
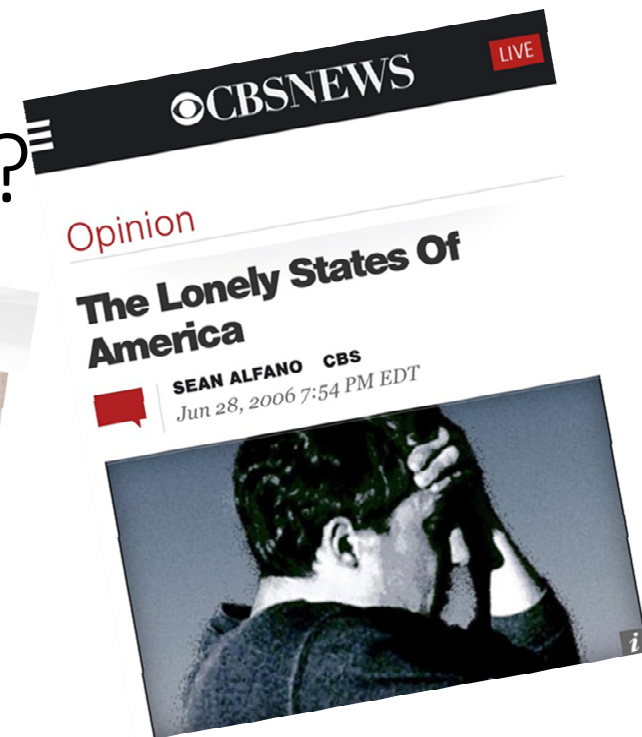
What is loneliness?

- Biopsychosocial model
 - Biological – e.g., personality
 - Psychological – e.g., depression, grief
 - Social – e.g., social isolation, lack of contacts, integration
- ‘Aloneness’ is not the same as loneliness
 - Being alone is not necessarily a negative experience
 - Alone time can be helpful in terms of facilitating self-regulation, reflection, creativity, concentration
 - A person may feel very lonely when surrounded by people



Who are more likely to feel lonely?

- Age
 - 5-16% of people aged 65+ in Britain (Ó Luanaigh and Lawlor, 2008)
 - But no clear relationship between loneliness and age
- Gender
 - Women report loneliness more frequently than men
 - but unequal distribution of risk factors
- Marital status
 - Marriage is somewhat protective
 - Non-married males most likely to report loneliness
 - Bereavement in older age is a major risk factor
- Other risk factors
 - Single parenthood, unemployment, low level of education, low income, informal caring, living alone, recent relocation, poor vision, hearing loss
- Longitudinal Finnish study:
 - Found that the onset of loneliness was more likely if people had become more depressed, had increased feelings of uselessness, increased feelings of nervousness, lost their partner and had reduced levels of social activity (Aartsen and Jylha, 2011)
- Longitudinal US study:
 - From 1985 to 2004, number of people without confidants tripled
 - One in four now have no confidants
 - More than half (53%) do not have non-family confidants (McPherson, Smith-Lovin and Brashears, 2006)



What are the consequences of loneliness?

- **Loneliness is a risk factor for poor physical and mental health**
- **Physical health**
 - Related to hypertension, poor sleep, abnormal stress responses (Bhatti and Haq, 2017)
 - Lonely or socially isolated individuals are at greater risk for all-cause mortality (Holt-Lunstad et al., 2015)
 - Loneliness significantly increases mortality rates in older people where it co-occurs with depression (Ó Luanaigh and Lawlor, 2008)
- **Mental health**
 - Depression and loneliness are strongly related and often occur together
 - Feelings of loneliness are associated with depression 3 years later (Green et al., 1992)
 - Loneliness predicts long-term trajectory in depressive symptoms (Heikkinen and Kauppinen, 2004)
 - Social isolation is a significant risk factor in suicide (Player, 2015)
- **Cognitive health**
 - Increased risk of Alzheimer's (Wilson et al., 2007)

Autism and loneliness

- DSM-V: ‘persistent deficits in social communication and social interaction across contexts’
 - Therefore, we might assume that autistic people are likely to experience loneliness
- People with autism may have differences in interpersonal relationship skills and experience fewer healthy social relationships compared to neurotypical people (Howlin, Goode, Hutton, & Rutter, 2004)
- Qualitative studies of autism in adulthood
 - anxiety, depression, social isolation, communication difficulties and occupational underachievement (Griffith et al., 2012; Hurlbutt & Chalmers, 2004; Jones et al., 2003; Müller et al., 2003, 2008; Portway & Johnson, 2005; Punshon et al., 2009)

Our research (Hickey, Crabtree & Stott, 2017): Levels of loneliness

ID	Gender	Age group	Loneliness	Depression	Anxiety
P1	M	60s	Moderate	-	Mild
P2	F	50s	Moderate	Severe	Severe
P3	M	60s	Moderate	-	Moderate
P4	M	50s	Severe	-	Moderate
P5	F	50s	Moderate	-	Mild
P6	M	50s	Moderate	-	Mild
P7	M	60s	Moderate	-	Moderate
P8	M	70s	Very severe	Moderate	Severe
P9	M	50s	Moderate	-	Mild
P10	M	60s	Moderate	-	-
P11	M	60s	Severe	-	Mild
P12	F	60s	Moderate	Mild	Severe
P13	M	60s	Very severe	-	Severe

Our research: isolation and loneliness

- Defining feature of growing up and getting older with autism
- No less distressing as people got older
 - *See, I never had many friends when I was younger. So I think in a way it's sort of prepared me for being on my own. Although I don't like it much. I've never liked it. (P12)*
- People particularly focused on the lack of a romantic relationship, describing longing
 - *I think I'm a born loner, quite frankly. And even no matter... Maybe I'm not the kind of person to have a life. Oh, I'd love it, with a person that would understand me. (P4)*
- Loneliness was less prominent in the accounts of the three study participants who had partners: one close relationship might help buffer effects of social isolation?
- ...But disconnection or being cut off were still features of their experience:
 - *It's not to do with not having friends and stuff like that. It's to do with I just feel that I'm totally isolated in myself. I don't know what to say to anyone; I can't connect. (P11)*

Our research: positive aspects of isolation

- Aloneness was sometimes framed positively
- Allowed uninterrupted pursuit of hobbies and interests, sense of achievement
 - *You know, where does lonely stop and isolated begin? I mean, I quite like my own company in some ways. Given that I'm quite hard-driven in my enthusiasm for certain things. (P13)*
- A place of safety
 - *I'm interested in machines. I can master them, if you like. I can understand them. I can relate to them; I can relate to machines better than I can people. Machines do not put you down. They don't criticise you, they don't hurt you and they don't make you cry. Not generally. People do that. (P4)*
- The potential of special interests to buffer distress
 - *A lot of [people with] Asperger's don't suffer from chronic depression because they have a narrow field of interest and they might have a job in that field of interest. Especially males. (P2)*

Our research: difference (pre-diagnosis)

- Once 'difference' was understood, individuals studied their peers and imitated their social skills. Over time, learned social skills became more habitual, enabling participants to 'fit in'
 - *When you emulate things long enough they become a habit. So they become – you actually outwardly become exactly like everybody else. But you aren't. You never – you never forget. You're never not autistic. (P10)*
 - *And I tried to smile like they smiled. And I think it helped me up to a point, to mix up with other people. But all the time I was hiding my true self. That was the problem. Inside I was feeling sort of bad. I wasn't really supposed to be like that. But it got me sort of with other people and that. (P12)*

Our research: reaching out (pre-diagnosis)

- Deliberate efforts to engage with people, especially in early adulthood
 - Clubs related to interests
 - Structured activities with definite start and end points
 - *It was a structured thing and I felt rather more comfortable with that. So yeah, we sort of did – we were meeting around another activity. If I'm not focused on trying to be friendly with someone it's actually easier to be friendly with them. (P11)*
 - Special interests:
 - *I perhaps should say my interest in [vehicle] registrations means that I've got a network of friends throughout the country and beyond. And I've sort of regularly, you know – we don't meet up very often but we're regularly emailing each other. (P1)*
- Just one participant gave up on trying to develop relationships

Our research: reaching out (post-diagnosis)

- Deliberate effort to gather additional information by meeting others with autism
 - Sense of shared experience and understanding
 - *You're accepted. You don't have to sort of hide anything. (P7)*
 - *The people, some of them are on my wavelength. (P3)*
 - Emotional support or friendship seeking seemed less important
 - Social comparison
 - *And I don't have these difficulties at all. And I travel around London quite easily. That's what my passion is, to travel around London. (P6)*
 - Normalising
 - *While we were just talking about various things, them saying, 'Oh, I have a problem with babies and noise.' And I used to be ashamed of that. (P9)*
 - Gaining knowledge
 - *They might come up with some problems they have – 'What do I do about this?' And I'm like, 'this is what you do.' And then, so I apply it to myself. That's what I ought to do about myself! (P8)*
 - Focusing on something tangible helped
 - *That's where we're focused on – it might be book club and we're focused on the book. But if you listen to the discussion on the book, it's very flowing and we can be really supportive. (P11)*

Reducing loneliness: what works?

- Group interventions with an educational focus or training input (active participation seems to work best)
- Targeting specific groups of people (e.g., widowed people, physically inactive people)
- No evidence to support use of 1:1 interventions at home

- (Cattan et al., 2005)



What might help reduce loneliness for people with autism? Advice for autistic adults

- Tips for improving quantity and quality of relationships
 - Small groups
 - Definite start and end points
 - Use special interest
 - Tangible focus (e.g., book club, creative writing) can be easier than unstructured
 - Be open about your diagnosis
 - Work to your strengths
 - if noisy bars are overwhelming, don't try to meet people there
 - If you know you struggle with a particular skill
 - ask people for help with this explicitly
 - observe socially skilled people on TV or in real life settings engaging in the skill (e.g., flirting)
- Tips for accessing other people with autism (informational support, acceptance)
 - Seek information on local autism support group after diagnosis (e.g., from GP or other health professional, library, search online for information)
 - Online autism groups might be useful for people without a local autism group
 - Or set up a local group!



What might help reduce loneliness for people with autism? Advice for families and carers

- *I normally find that to explain the mysteries of the neurotypical mind, I would go to the person called [Group Facilitator], that's the person who runs the – most of the groups I go to. And she's normally very good at that side of thing. She explains neurotypicals better than anyone I know to me. So I understand – that's how I understand you lot! (P11)*
- Provide 'neurotypical perspective' on social interactions that are difficult to comprehend
- Offer constructive feedback on social skills
 - need to know what to do, not just what not to do
 - offer modelling and practice
- Find out about and encourage attendance at local social events and possibly attend together until person with autism feels comfortable

What might help reduce loneliness for people with autism? Advice for professionals

- Always provide information on autism-specific groups
 - Might be particularly important immediately post-diagnosis
- Many people on the spectrum develop ways of masking symptoms, but some do not and require help
 - Professional-led social skills groups may be effective for improving social knowledge and understanding, improving social functioning, reducing loneliness and potentially alleviating psychiatric symptoms (Spain & Blainey, 2015)
 - Can increase skills necessary to access community-based groups
 - Feedback on groups suggest participants want more explicit focus on romantic relationships (Spain & Blainey, 2014), so professionals should specifically provide this
 - Emphasis on early intervention treatments means that interventions that might be important in adult life, such as dating skills, are under-developed (Shire, 2013)

What might help reduce loneliness for people with autism? Advice for professionals

- Role of statutory services in developing support networks
 - Evidence from mental health groups of benefits of such groups (Crabtree et al, 2010)
- Consideration of models of care short term intensive vs long term low level
- Identification and diagnosis – still an issue, especially in older adults
- Bullying, abuse and stigmatisation – raising awareness
- Avoiding inappropriate friendships, mate hate, social vulnerability

Questions?



References

- Aartsen, M and Jylhä, M (2011) Onset of loneliness in older adults: results of a 28 year prospective study. *European Journal of Ageing*, 8, 31–38.
- Bhatti A, Haq A (2017) The pathophysiology of perceived social isolation: effects on health and mortality. *Cureus* 9(1): e994. DOI 10.7759/cureus.994
- Cattan M, White M, Bond J, et al. (2005) Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing & Society* 25:, 41–67.
- Crabtree JW, Haslam SA, Postmes T, et al. (2010) Mental health support groups, stigma, and self-esteem: positive and negative implications of group identification. *Journal of Social Issues* 66(3): 553–569.
- Green BH, Copeland JR, Dewey ME, et al. (1992) Risk factors for depression in elderly people: A prospective study. *Acta Psychiatrica Scandinavica*, 86, 213–7.
- Griffith GM, Totsika V, Nash S, et al. (2012) ‘I just don’t fit anywhere’: support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism* 16(5): 532–546.
- Hickey A, Crabtree J and Stott J (2017) ‘Suddenly the first fifty years of my life made sense’: Experiences of older people with autism. *Autism*, 1-11.
- Holt-Lunstad J, Smith TB, Baker M, et al. (2015) Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspectives on Psychological Science* 10: 227-37.
- Hurlbutt K and Chalmers L (2004) Employment and adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities* 19(4): 215–222.
- Jones RSP, Quigney C and Huws JC (2003) First-hand accounts of sensory perceptual experiences in autism: a qualitative analysis. *Journal of Intellectual & Developmental Disability* 28(2): 112–121.
- McPherson M, Smith-Lovin L and Brashears ME (2006) Social isolation in America: changes in core discussion networks over two decades. *American Sociological Review*, 71(3): 353-375.

References

- Müller E, Schuler A and Yates GB (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism* 12(2): 173–190.
- Müller E, Schuler A, Burton BA, et al. (2003) Meeting the vocational support needs of individuals with Asperger syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation* 18(3): 163–175.
- Ó Luanaigh & Lawlor (2008) Loneliness and the health of older people. *International Journal of Geriatric Psychiatry* 23: 1213–1221.
- Peplau L and Perlman D (1982) *Loneliness: A Sourcebook of Current Theory, Research and Therapy*. New York: Wiley-Interscience
- Player MJ, Proudfoot J, Fogarty A, et al. (2015) What Interrupts Suicide Attempts in Men: A Qualitative Study. *PLoS ONE* 10(6): 1-13
- Portway SM and Johnson B (2005) Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society* 7(1): 73–83.
- Punshon C, Skirrow P and Murphy G (2009) The 'not guilty verdict': psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism* 13(3): 265–283.
- Shire (2013) Dating on the autism spectrum: What it's like to look for romance when "a big smile can be frightening". *The Atlantic*: <https://www.theatlantic.com/health/archive/2013/08/dating-on-the-autism-spectrum/278340/>
- Spain D and Blainey SH (2015) Group social skills interventions for adults with high-functioning autism spectrum disorders: a systematic review. *Autism* 19(7): 874–886.
- Weiss, R.S. (1973) *Loneliness: The Experience of Emotional and Social Isolation*. Cambridge, MA: MIT Press.
- Wilson RS, Krueger KR, Arnold SE, et al. (2007) Loneliness and risk of Alzheimer disease. *Archives of General Psychiatry* 64: 234–240.