

Autistic young adults and their understandings of their mental health

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About the study

- Autistic young adults with no learning difficulties
- Face to face interviews about:
 - experiences of emotional distress / mental health problems
 - how make sense of those experiences
 - and how this impacts on how manage and respond
 - experiences of using mental health services
- Sample
 - 19 young adults (M=17, F=2)
 - 23-24 years
 - Represent range of experiences of mental health problems

Experiences of emotional distress / mental health problems

- Words commonly used to describe everyday experience
 - worried, anxious, stressed, nervous, awkward, depressed, introverted, frustrated, lonely, annoyed, angry, exhausted.
- Everyday but less often mentioned
 - feeling paranoid, uncomfortable, overwhelmed, pressured, nauseous and unable to cope.

“...they’re like synonyms... alternatives to describe roughly the same feeling ... all these bad feelings...” (DY04SM)

Understandings of mental health & autism: 'normal' but different

- Anxiety and low mood: a shared experience among autistic people
 - 'Normal' but different
 - Intensity
 - Duration

...it's normal to feel stressed... but I might feel stressed a little bit more. (YA06SF)

- Unlikely to be 'evaluated' against external reference points
- Likely to remain private / hidden

I don't feel like it's really easy for me to really confide in anybody. I think with [support worker] I could finally find someone I could confide in, but... after things turned out the way they did [the support worker left]... It just all fell apart. I just fell apart, me. (DY01SM)



Understandings of mental health & autism: increased vulnerability

- Three factors/mechanisms
- More likely to experience stress / anxiety feelings / symptoms
- Hinders adaptive responses / cope differently
- Difficulties with communicating feelings
- Cyclical pattern of reinforcement
- ...cont'd...



■ events/situations more likely to cause stress / anxiety

■ hinders adaptive responses / cope differently

...the anxiety definitely is part of [autism]... I suppose everyone gets anxious... But most people are good at putting it to the back of their mind... I can't... I try to and then suddenly it just brings itself forward again. (YA01SF)

...it's managed differently... regular people, for example, if they've got anger and frustration... they'll know what they need... there's that barrier there with people with Asperger; the anxiety and the... lack of confidence. (DY07SM)

■ difficulties with communicating feelings

People did ask that; if you need help... you don't know if they mean it or not... I don't know how to communicate my problems and when people ask you think, in your mind, do they actually want to help. I don't know, you don't know how to communicate your problem to people, even to close friends of mine. (YA08SM)

Previous experiences of seeking help with mental health difficulties

- Many accounts of very difficult times in their lives
 - school, transition, work, loss of key support
- Very little experience of receiving mental health support as children and teenagers
- Experiences typically negative
 - unsatisfactory
 - incomplete

... you make progress... but then that psychologist tries to leave, passes on everything to someone else and then it all gets lost and forgotten about. (DY01SM)

Consequences

- Emotional / mental health difficulties are to be 'endured'
 - a constant presence
- 'Self-management' can be highly effortful
 - ...most I've ever tried to do is ignore it... keep my mind preoccupied on something else to try and get the anxious out, but that's quite difficult. (YA05SM)
- Self-management is private
 - ...you just go into ... I call it my retreat. (YA08SM)
- Strategies may not be adaptive / effective
 - withdrawal
- Help-seeking is regarded as irrelevant / futile
 - I don't know if I'd ever be inclined to try and seek out a counsellor now... I'd rather just find out which of my friends are more open to the idea of me going to them if there's anything on my mind (YA10SM)

Accessing mental health support: parental role

- Barrier to understanding and help-seeking
 - beliefs about autism / mental health
 - previous experiences

I asked mum and dad, I was saying "Oh do you think I need to see a psychiatrist?" and they said "No". So I've always assumed that I didn't then, but I've always thought that maybe if I did get a psychiatrist it would have helped. (YA05SM)

- Knowledge/skills to discern adaptive vs non-adaptive responses / well-being
- Facilitate or initiate contact with primary care
 - triggered when symptoms affecting physical health

...it was quite severe... I could see myself dropping in weight. (DY07SM)

Conclusions and implications

- A number of factors increasing risk for mental health difficulties and for them remaining unsupported or unaddressed
 - many are amenable to intervention
 - ...no quick wins
- Improving family understanding of autism
- A preventive approach from diagnosis onwards: 'upskilling' / supporting self-management
 - parents
 - children and young people
- Primary care – awareness and skills
- Autism-specialist mental health support available
- Improving the school experience