"You have to find it yourself": Experiences of support following adult autism diagnosis

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Project aim
To understand how adults perceive and navigate formal and informal support after autism diagnosis

Background

Changes in the public and professional understanding of autism over past decades has led to more adults receiving first-time autism spectrum diagnoses. Research shows that diagnosis is generally perceived as a positive event, but there is a lack of suitable support services for this age group. Researchers have also begun to examine informal sources of support such as family, intimate partners and autistic peer groups. Understanding the roles and meanings of both formal and informal support would help us find ways to provide optimal support to adults after diagnosis.

Method

Australian adults (n=12, age 25-83, 4 male, 6 female, 2 non-binary; 3 with intellectual disability) who received first-time autism diagnoses at age ≥18 took part in individual semi-structured interviews. We developed an interview schedule involving initial diagnosis, support experiences, and desired areas of support with advisory input from autistic adults and adults with intellectual disability. Interviews were conducted via participants' preferred formats including face-to-face (n=1), video link (n=2), telephone (n=2), instant messaging (n=2) and email (n=5). Thematic analysis was conducted to identify recurrent patterns of meaning across responses.

Results

Social relationships
- Many autistic people desire social connection, but are socially isolated
- Family, partner and friends provide emotional support and help to find professional services
- Diagnosis helps support persons understand and relate better with autistic adults
- Pressure to act neurotypical is a source of discomfort
- Desire for authenticity and support versus fear of discrimination and being disbelieved when disclosing diagnosis

> "People seem to think that once you're an Aspie, you're either Sherlock Holmes or you're the Sheldon kind."
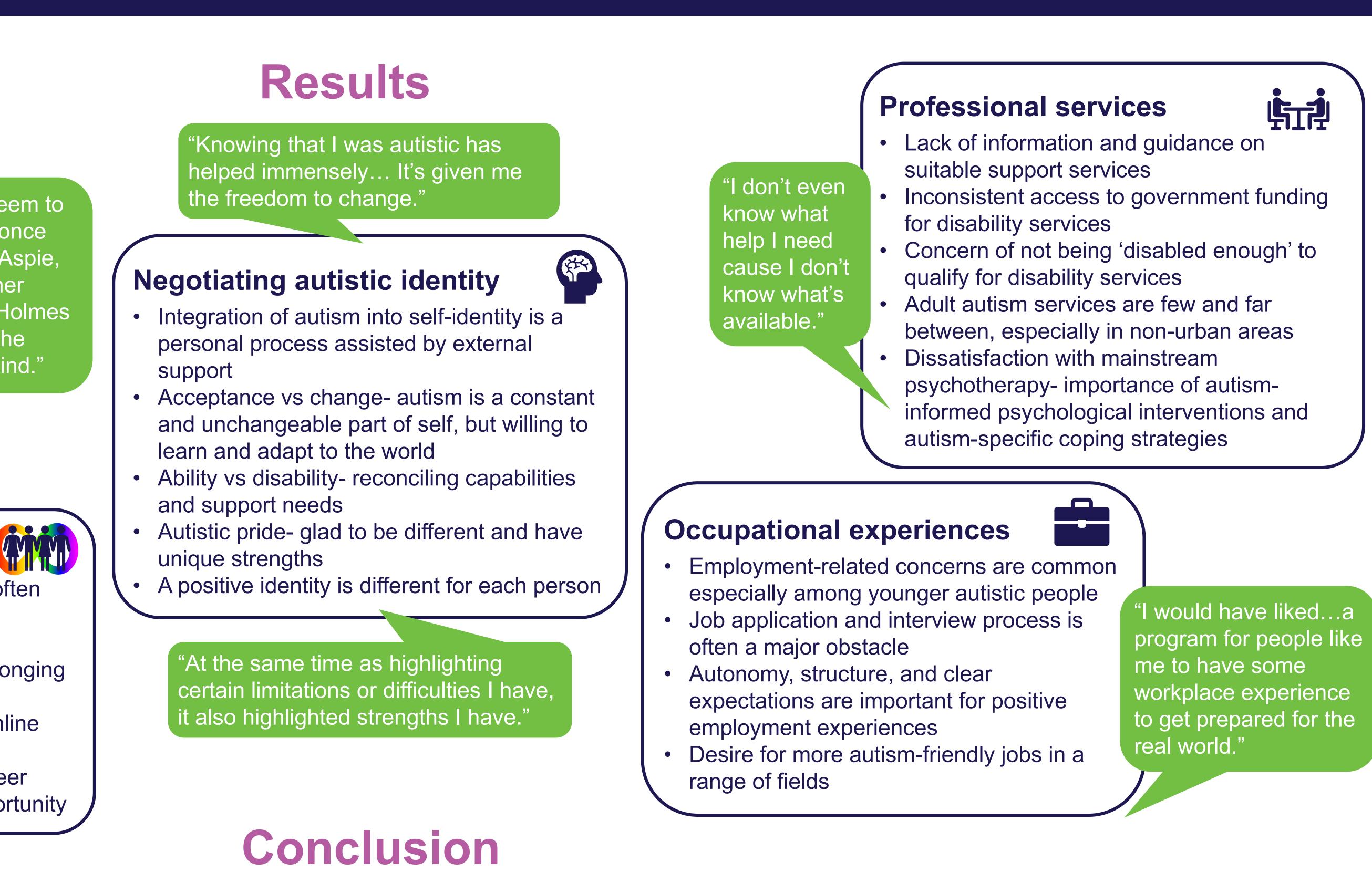
Autistic encounters
- Interactions with other autistic adults often occur online
- Autistic peers are valuable for sharing experiences, advice, and sense of belonging
- Focus on negative experiences and arguments are unhelpful aspects of online autistic spaces
- Many would like to attend in-person peer support groups, but few have the opportunity

> "What many people crave is a real community, and it's so different for an autistic person."

> "Knowing that I was autistic has helped immensely… It's given me the freedom to change."

Negotiating autistic identity
- Integration of autism into self-identity is a personal process assisted by external support
- Acceptance vs change- autism is a constant and unchangeable part of self, but willing to learn and adapt to the world
- Ability vs disability- reconciling capabilities and support needs
- Autistic pride- glad to be different and have unique strengths
- A positive identity is different for each person

> "At the same time as highlighting certain limitations or difficulties I have, it also highlighted strengths I have."

Professional services
- Lack of information and guidance on suitable support services
- Inconsistent access to government funding for disability services
- Concern of not being 'disabled enough' to qualify for disability services
- Adult autism services are few and far between, especially in non-urban areas
- Dissatisfaction with mainstream psychotherapy- importance of autism-informed psychological interventions and autism-specific coping strategies

> "I don't even know what help I need cause I don't know what's available."

Occupational experiences
- Employment-related concerns are common especially among younger autistic people
- Job application and interview process is often a major obstacle
- Autonomy, structure, and clear expectations are important for positive employment experiences
- Desire for more autism-friendly jobs in a range of fields

> "I would have liked…a program for people like me to have some workplace experience to get prepared for the real world."

Conclusion

Autism diagnosis in adulthood is a momentous event that leads to greater self-discovery. Professional services and interpersonal support are both important for improving everyday functioning and supporting positive identity development. Our analysis highlighted that guidance on finding support, autistic peer support groups, autism-friendly employment, and autism-informed psychotherapy as priorities for developing support services for this population. Additionally, strategies increasing public understanding and decreasing autism stigma would help create supportive social environments for autistic adults.

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