

What the Research Tells Us about Outcomes for Individuals with Asperger Syndrome

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**Do you feel like you have
stepped onto this ride?**



Review of Research Literature

- Anecdotal reports
 - Autobiographical and biographical accounts (e.g., Newport, 2001; Shore, 2003; Willey, 1999)
- Case studies
 - Asperger 1944 and Wing 1981 reported highly variable outcomes
- Group studies
 - Few lived independently (Tantam 1991; Newson, Dawson, & Everard, 1982)

Longitudinal Studies

- Because of problems associated with differential diagnosis, Howlin (2000) combined results of 6 studies of individuals with HFA and AS in her review of research literature on outcomes in adult life
- Samples sizes ranged from 9 to 43
- Mean ages ranged from 18-38 years

Howlin's (2000) Lit Review

- College education: 7% to 50%
- Semi independent to dependent living arrangements: 16% - 50%
- Engaged in paid work: 5% to 55%
- Psychiatric disturbance: 9% to 89% (mostly depression and anxiety)
- Few married: 0 to 2 participants in each study

Howlin, Goode, Hutton, & Rutter

2004 Study

- 68 individuals with nonverbal IQ > 50 (AS not a separate diagnosis)
- Individuals with IQs > 70 were likely to do well, but also had highly variable results
- Results suggested that ability to function adequately in adulthood might depend on degree of support offered by families, employment, social services, as well as IQ.

“Although high-functioning people with autism or Asperger syndrome may succeed well as adults, such achievements rarely come easy.”

» Howlin, 2000, p. 79

Engstrom et al.'s 2004 Study

- 42 adults with HFA & AS from Sweden
- Majority lived independently; however, very few lived in “normal” psychosocial conditions and most lived alone (p. 109)
- 1 employed; None married; None had children
- Most needed high level of public or private support
- **Independence may also have been based more on public strategies for individuals with disabilities than on actual social ability.**

Critical Areas of Concern

- Employment issues
- Comorbid mental health conditions
- Physical health conditions
- Neurological issues (motor skills and insomnia)
- Sensory issues
- Social cognition
- Problems with legal system
- Mortality rates

Employment Challenges

- Finding vocational niche
- Getting through the job interview
- Finding work commensurate with their ability levels (Romoser's "Malemployment")
- Maintaining employment
- Negotiating social relationships

Hurlbutt & Chalmers 2004 Study

- Adults with AS reported biggest obstacles in maintaining employment were:
 - Poor social communication between employee and employer or coworkers
 - Social skills deficits
 - Sensory issues

Comorbid Mental Health Conditions

- Tsai (1996) reported that ASD usually appears with comorbidity.
- Depression most common in adolescents and adults. Difficult to establish prevalence rate.
- Suicide rates higher than for general population (Wing, 2000).
- Difficulty in expressing feelings may be misinterpreted as psychotic symptoms.
- MMPI-2 showed higher scores in social isolation, interpersonal difficulties, depressed mood, and coping strategies for those with AS and HFA as compared to controls (Ozonoff et al., 2005).

Physical Health Conditions

- 12 men (ages 18-21) with AS reported dissatisfaction with physical health in following areas:
 - Discomfort and pain
 - Dependence on medical treatment
 - Activities of daily living
 - Work capacity
 - Energy
 - Mobility
 - Rest

» Jennes-Coussens, Magill-Evans, & Konig, 2006

Motor Skills

- ICD-10 criteria indicate that clumsiness is frequently associated with AS.
- Tani et al. 2006 found deficits in fine and gross motor skills persist into adulthood.

Sleep Disturbance

- Not clear yet whether insomnia is due to AS itself, comorbid psychiatric disorders, or a combination of both.
- May be explained by a higher prevalence of anxiety, fear, or social behavior problems.

» Oyane & Bjorvatn, 2005

Sensory Issues

- Heightened sensory awareness is “an internal human ‘normality’ with the volume turned up” (Williams, 1998, p.9).
- Grandin (1995) reported that noise sensitivity, oversensitivity to touch, and difficulties with rhythm cause behavior problems, which are frequently overlooked by service providers (Aylott, 2000).

Social Cognition

- “An extreme form of egocentrism with the resulting lack of consideration for others” (Frith, 2004, p. 676)
- Appears to be nondeliberate and causes difficulties in long-term interpersonal relationships
- Advantages and disadvantages of Internet

Legal System

- Little documentation of excessive crimes among people with AS, despite some media descriptions (Howlin, 2000).
- They may even be more law abiding because of the very rigid way many individuals tend to keep rules and regulations.
- May be set up by more savvy peers to be accomplices to crimes or unlawful activity without being aware of this.

Mortality Rates

- Mortality rates of individuals with ASD below age 30 were higher (2%) than general population (0.6%)
- More severely intellectually disabled (accidents and physical causes) and those with normal intelligence (risk of suicide) were associated with a higher risk of death
- More research is needed in this area.

» Isager, Mouridsen, & Rich, 1999

Treatment

- Behavioral and pharmacological treatments do not have an effect on the underlying impairments of AS; they just treat the symptoms
- Education-based strategies focus on changing eccentricities into strengths and also provide direct instruction of information and social skills
- To be effective, must be a collaborative effort.

Recommendations

- Increased public awareness targeting medical professionals and educators so that diagnosis and services can be given earlier.
- Also educating the public so that they can better understand how live with individuals with AS in their community.
- Healthcare professionals can “disable the people they are seeking to support by not responding appropriately to their needs” (Aylott, 2000, p. 857).
- Educational services and employment opportunities need to be available.

- “There is little to support the view that individuals with a diagnosis of Asperger syndrome should be deprived of services that are available for those with a diagnosis of autism, or that educational management programs should differ in any way. Instead it should be recognized that for *all* high-functioning individuals with an autistic spectrum disorder there is need for much improved services throughout childhood and adulthood, if the long-term outcome is to be significantly enhanced.

» Howlin, 2003

Prospectus

- One model of supported employment in UK originally started as an innovative pilot program to address more able individuals in and around London.
- Support was found to be critically important during 1st few weeks of employment (Howlin & Mayhoo, 1996).
- Once employee is settled and has gained confidence, the support is gradually reduced.
- Study found the need for flexibility within supports as individuals experience changes in work or have problems that may indicate they need a temporary boost in the number of support hours needed.

» National Autistic Society, 2006

Prospectus

No cost to employer for following services:

- Orientation of client as to where things and people are in the place of employment
- Identification of training needed
- Job analysis including guidelines or task analysis
- Structure including breaking down the day and making time plans
- Disability awareness training for colleagues
- Social training awareness and instruction on nonwritten rules of workplace
- Development of effective working relationship between employee and line manager

» National Autistic Society, 2006

Specialisterne

- Founded January 2004 by Thorkil Sonne after his son was diagnosed with ASD.
- First company in the world to base its concept on employing people with ASD.
- “The company’s goal is to change the world’s view about autism – and demonstrate that a person with ASD can develop into a skillful and valuable employee capable of contributing to society on an even par with everyone else.”

Specialisterne

- Utilizes the special abilities of those with autism to solve valuable tasks such as programming, software testing and data registration.
 - Engagement
 - Persistence
 - Precision
 - Focus on details
 - High learning ability
 - Structured way of learning
 - Ability to follow instructions

Specialisterne

- 40 employees, 31 with ASD, located in Denmark
- Plans to increase to 1,000 employees with ASD internationally
- Partnership with LEGO Education
- Clients include Microsoft, TDC, KMD, CSC
- 1% of all tasks in any large company will be suited very well for Specialisterne employee
- Sonne believes that “specialists” of society are needed on the labor market, and certain tasks are solved better by a specialist than by a “generalist.”
- www.specialisterne.dk

Specialisterne Provides

- **For Employee**

- Limited stress
- Training
- Structured work methods
- Personal support
- Clear instructions
- Tailored working environment
- Development plans tailored to individual
- Working hours according to individual threshold

- **For Customers**

- Single point of contact
- No special understanding needed
- Limited risk
- Full responsibility for quality work
- Matches customer needs with employee's skills
- Choice of where tasks will be solved (customer's premises or Specialisterne)

Future Directions

- Research needs to continue to address issues associated with differential diagnosis of AS so that effective interventions can be determined.
- Ask individuals with AS directly about their perceptions of their areas of strength and areas of need.
- More employment models like Prospectus and Specialisterne are needed to assist individuals in finding their niche and becoming successful in the work world.
- Research needed on key supports services necessary for successful employment.
- Different housing options need to be explored.
- Provisions need to be in place for time when those with AS outlive their parents.