

Adults with Autism: A Systematic Review of Community Participation

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Abstract

A systematic review of the literature was conducted to investigate what is currently known about community participation, social functioning, support, independence, and recreation for adults with autism spectrum disorders (ASD). 12 studies were identified, evaluated for strength of evidence and organized into topical themes. These studies discussed community participation from the perspectives of support, social functioning, and quality of life (QoL).

Background

The symptom profile in autism spectrum disorders (ASDs) changes across the lifespan, with most individuals showing modest to significant improvements across core and associated symptom areas. However, deficits in language, communication, and social interaction skills generally linger and can have significant effects on adult outcomes (Billstedt, Gillberg, & Gillberg, 2007).

- Even high functioning individuals with ASD often seem to "function well below the potential implied by their normal range intellect" (Marriage, Wolverton, & Marriage, 2009, p. 326).
- Patterns of unemployment or underemployment, limited friendships and romantic relationships, and relatively low levels of independence have been seen across outcome studies (e.g. Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004; Marriage, Wolverton, & Marriage, 2009).

Adults with ASD tend to show lower levels of community participation:

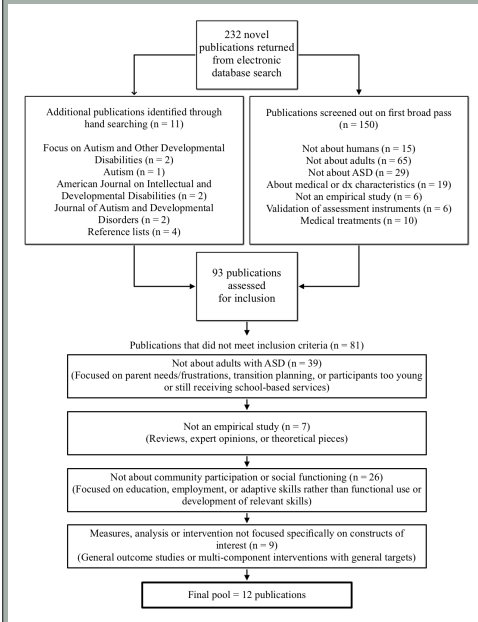
- Participation in social and recreational activities is related to individual characteristics (e.g. lower levels of impairment in social skills, greater independence) and environmental characteristics (e.g. family support). (e.g. Liptak, Kennedy, & Dosa, 2011; Orsmond, Krauss, & Seltzer, 2004)

Purpose

The purpose of this review was to investigate levels of independence in social functioning and community participation for adults with ASD and to identify supports facilitating improved participation and social functioning that are currently effective or that may be shown to be effective in the future.

Search Strategy and Analysis

- A comprehensive search of peer-reviewed journals using electronic databases (PsycINFO, PsycARTICLES, PubMed, and ERIC) was completed using the following search terms: "adult" AND "autism", "ASD", "Asperger" OR "pervasive developmental disorder" in combination with "social", "familial", "sibling" OR "friend" AND "independent" OR "support", and excluding articles that included the terms "employ" or "vocat" in the title and were published before 1995.
- The identified studies were appraised for quality and analyzed for topical themes revealing two main constructs: quality of life (QoL), and social functioning.



Participants

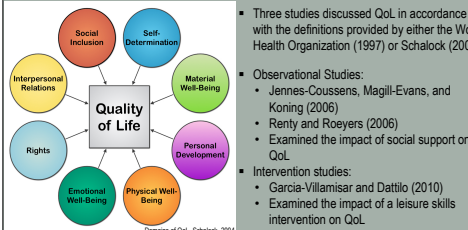
	Characteristics	Comments
Gender	Males: 56-100% Females: 0-44.1%	There was a somewhat higher percentage of females than would have been expected, especially given the generally high level of functioning seen across participants.
Age	Overall: 17-77 Average: 19-43.52	The majority of participants were between 20-40 years of age.
Diagnosis	AS: 30.8-100% PDD-NOS: 9-30.8% Autism: 7.7-75.8% ASD: 34.2-36% HFA: 11.1-37.5%	AS was by far the most common diagnosis, comprising an average 63% of participants across the eight studies that reported a breakdown of participant diagnoses.

Independence was evaluated mainly through the use of objective measures within the domains of education, employment, and living arrangements. These data are briefly discussed here as demographic characteristics.

Domain	Characteristics	Number of Studies Reporting
Living Situation	Independent living: 6.3-48.6%	4
	Still living with parents: 26.6-94.1%	4
Employment	Regular full-time employment: 6.3-37.1%	7
	No daily activities: ~24.1-50%	Estimate
Education	Still in college (college-age): 16.7%, 100%	2
	Undergraduate degree: ~25%	2
	Undergraduate or graduate degree: ~50%	2

Note: Data reflect participants in only one of the studies. Two reported no data in these areas, and one included only participants with very high levels of independence (Renty & Roeyers, 2007); including them in these areas masked the lower levels that were more commonly seen across the other studies.

Quality of Life (QoL)



Important Findings:

- Young adults with ASD appeared to have QoL that was lower than their neurotypical (NT) peers, with particular impact deriving from deficits related to the social domain.
- Unsatisfied formal support needs were related to poorer QoL.
- Perceived informal social support emerged as a highly important predictor of QoL.
- Intervention efforts should take a holistic approach, using person-centered planning practices and assessment of met and unmet need and existing environmental supports (Jennes-Coussens et al., 2006; Renty & Roeyers, 2006).
- Garcia-Villamisar and Dattilo (2010) found that using a person-centered approach to teaching and supporting leisure skills and participation in leisure activities can help to reduce stress and may be one possible route to improved QoL for adults with ASD.

Directions for Future Research:

- Effective strategies to bolster the quality and supportiveness of informal support networks should be developed.
 - While individuals with ASD often do not have highly populous social networks, the perceived readiness of the social network to offer support may potentially be more important than the number of people in the social network.
- Use of training strategies with specific individuals in an environment, e.g. educating employers about how to help avoid issues in the workplace should be further trialed.
 - The use of peer training strategies has been investigated for students with ASD (e.g. Carter & Pesko, 2008); these strategies may be applicable for training specific individuals or supporting specific situations that are problematic for adults with ASD.
- While consideration of environmental variables is certainly important, it is also necessary to further focus on developing interventions that increase the skill set of the adult with ASD and improve his or her ability to interact with others and participate in the community.
- Interventions should be further developed that address other complex yet important skill areas related to QoL, such as self-determination and related component skills (e.g. autonomy, self-advocacy) (e.g. Wheeler, Shogren, Smith, Zager, & Simpson, 2010).
- Jennes-Coussens et al. (2006) suggested that intervention should address more sophisticated abilities than just what is required to survive.

Social Functioning

- Nine studies discussed social functioning in adults with ASD, investigating how the individual with ASD functioned or developed skills to function socially within his or her community environment. Social functioning was discussed most frequently in terms of social skills development and engagement in or supports for reciprocal interactions with others.
- Observational Studies discussed the impact of support group participation and informal social support on social functioning.
 - Jantz (2011) (mixed methods)
 - Renty and Roeyers (2007)
- Qualitative Studies investigated social support needs and support groups, community involvement, and social functioning.
 - Jantz (2011) (mixed methods)
 - Müller, Schüler, and Yates (2008)
 - Sperry and Mesibov (2005)
 - Engström, Ekström, and Emission (2003)
- Intervention Studies investigated the impact of social skills groups and support groups on social functioning and community involvement.
 - Gantman, Kapp, Orenski, and Laugeson
 - Hillier, Fish, Cloppert, and Beversdorf (2007)
 - Turner-Brown, Perry, Dichter, Bodfish, and Penn (2008)
 - Howlin and Yates (1999)

Important Findings:

- Informal supports from friends and families were important for social functioning.
- The majority of the adults in these studies reported desiring social contacts, but sparsity of relationships often lead to increased loneliness.
 - Increased participation and interaction with others as well as support provided by family members resulted in decreased loneliness (Gantman et al., 2012).
- Individuals who had a higher number of close friends who were family members were more likely to have close friends who were not family members (Jantz, 2011).
- Adults with ASD generally enjoyed and benefitted from participating in support groups.
 - Participants discussed feeling a sense of community in groups with other adults with ASD.
- Participants discussed conditions that they found supported community participation. These included shared interest activities, outdoor or creative activities, and highly structured small group settings. Many of these required very little social interaction (Müller et al., 2008).

Directions for Future Research:

- Training for families in building strategies for supporting social functioning from a place of patience, understanding, and tolerance should continue to be investigated.
- Participants may have various goals for group membership including social skills development, participation in recreational activities, and development of friendships.
 - Informal support groups may not readily fulfill these goals. Research should work to identify the most effective group model, type, structure, and content to match different goals, and participants' goals should be matched to what the group can actually provide.
 - Gantman et al. (2012) emphasized the importance of addressing both receptive and expressive social communication skills during group interventions; this should be considered in future design efforts.
- While some discussed the benefit of being able to learn through observation of NT adults, explicit social skill instruction is often necessary for individuals with ASD.
 - Effective methods for combining and balancing formal social skills instruction with informal social support groups should be investigated.
- Hillier et al. (2007) noted that individuals with ASD "often know the social rules and can learn the skills but do not know how to apply those skills" (p. 108).
 - Effective generalization strategies should be further developed; these may include the use of homework, role-plays, or implementation of community-based learning.
 - Friendships with NT adults may provide an opportunity for practice and generalization.
- It has been observed that group members tend to interact mainly through the facilitator rather than directly with each other and often desire a high level of structure (Jantz, 2011).
 - Strategies should be developed to enable lower levels of facilitator involvement and increased direct interaction between group members; this may help support members in accomplishing the goal of greater social interaction and development of friendships. To this end, Jantz (2011) suggested that having a co-leader may be beneficial.
 - The potential utility of incorporating interventions in social problem-solving for increasing the ability of adults with ASD to work together to generate the complex, abstract, and flexible solutions that can help enhance social functioning should be explored.

Conclusions

Participation in social and recreational activities in the community can help an individual build communication skills, form friendships and other relationships, and establish natural support networks. Social skills deficits are related to poorer than expected functioning across a variety of areas for adults with ASD, and provision of supports for community participation and social skills instruction into adulthood should be more commonplace. As Howlin and Yates (1999) discuss, running social skills groups and informal support groups is neither very expensive nor very time-consuming and could make a significant difference for adults with ASD. Adults with ASD can benefit from interventions targeting skill development at the individual level, development of environmental supports, formal social skills instruction, and informal support groups, as well as community-level interventions designed to increase knowledge about autism and acceptance and understanding of individuals with disabilities. Greater attention to fostering generalization of social skills across settings should be an area of focus for the future.

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