

Research Paper

Transition to community by adolescents with Asperger syndrome: Staying afloat in a sea change

Ellen Giarelli*, and Kathleen Fisher

Drexel University College of Nursing and Health Professions, 1505 Race Street, Bellet/526, Philadelphia, PA 19102, USA

Abstract

Background: Transition to community (TC) is the movement out of secondary school to independent living or higher education. It is challenging for young people who have typical neurodevelopment and daunting for those who have neurodevelopmental characteristics associated with Asperger syndrome (AS).

Objective: This grounded theory study describes the phenomenon of transition to community among adolescents and young adults with AS.

Methods: Audiotaped interviews were transcribed verbatim and analyzed using constant comparison to explore the socially constructed phenomenon of TC. Our sample comprised 36 participants from four groups deemed central to the phenomenon including: individuals with AS age 18–22 years ($N = 13$), parents ($n = 13$); and five each of educators and potential employers.

Results: The core psychosocial problem of TC is to stay afloat while feeling “adrift.” This problem was experienced by the individual with AS, and parents and others were observers and facilitators. Adolescents, with the support of parents, teachers and sympathetic employers solved this problem by using three psychosocial processes of structuring, anchoring, and embarking.

Conclusions: Clinicians who work with this population, potential employers, and educators are stakeholders who can apply our findings to the development of effective and personalized transition services. Findings from our study are grounded in the experiences of participants, and therefore, have explicit practical value. The conceptual model of TC can be used by health care providers, educators, employers and parents to guide adolescents as they transition to community. © 2013 Elsevier Inc. All rights reserved.

Keywords: Asperger syndrome; Transition to community; Adolescents; Grounded theory

Central to transition to community (TC) is the need to identify and work independently toward achievable goals such as post-secondary education, vocational training, employment, and independent living. Responsibilities shift from adult caregivers to the adolescent as (s)he leaves the home for social independence. Theorists such as Erikson¹ and Havinghurst² posited that emerging adults must be able to self-regulate and adjust to ever-changing social contexts.

Transitioning challenges a young person to acquire self-efficacy skills such as seeking knowledge about one’s health problems, self-determination, advocating for oneself in work, and in the larger social community. This is challenging for young people who have typical neurodevelopment and daunting for those who have neurodevelopmental characteristics associated with Asperger syndrome (AS), which may

include: impaired social reciprocity, a need for sameness, resistance to change, and sensory processing difficulties such as noise or light sensitivity.

Background

Classified as a pervasive developmental disorder,³ AS is at the high-functioning end of spectrum of autism disorders. Persons with AS exhibit impaired conversation skills, impaired relationships, may inappropriately use nonverbal behaviors to regulate social interaction (e.g., eye-to-eye gaze, facial expression, body posture), and lack social or emotional reciprocity.⁴ They may manifest restrictive, repetitive and stereotypical patterns of behavior and activity; or be preoccupied with an interest, routine, or motor mannerism. Language development and cognitive ability are often unaffected³ and language skills and memories may be superior. A core feature of resistance to change can be found among people with AS. This has been observed as adherence to strict, procedures, routines, and rituals. For example, one may always wear the same item of clothing, do certain activities in exactly the same

The authors declare no conflicts of interest with respect to the authorship and/or publication of this article.

Authorship Statement: The submission of the manuscript has been approved by all co-authors.

* Corresponding author. Tel.: +1 215 762 7086; fax: +1 215 762 4080.

E-mail address: imlng@aol.com or eg446@drexel.edu (E. Giarelli).

sequence or manner, or people with this characteristic may become anxious if prevented from following the routine or rituals. Resistance to changing one's routine may involve any number of behaviors and situations, and is germane to the phenomenon of TC because during transitioning the adolescent must adapt to a new social milieu, follow instructions and procedures designed by someone else, assume greater responsibility for self-care, and interact with a widening circle of acquaintances.

Transition programs for AS

The US Congress enacted the *Individuals with Disability Education Act* (IDEA) and the 1997 Amendments, which contained regulations that mandated transition planning for students with a disability.⁵ Transition planning must include evaluations of the student's needs, preferences and interests, and social-skills training in self-advocacy and career awareness.⁶ Despite this law, transitioning remains a difficult process and the effectiveness of transitioning programs vary across communities.⁷

Szatmari and colleagues studied this population and reported^{7–9} that social functioning improved among children with AS as they approached adulthood. This was attributable to high intellectual ability. Even so, young adults with AS, were largely unemployed and socially isolated.^{10,11} Other researchers reported behavioral profiles tended to worsen after leaving high school, due to the reduction in the level of stimulation at school,¹² and the loss of follow-up services.¹³

Based mostly on review of expository literature, Lawrence and colleagues¹⁴ proposed the use of a transition assessment guideline. Those with AS have difficulties interpreting social cues and relating to peers, thus their study focused on transitions to adulthood with the goal of independent living. They concluded from the literature that many with AS continue to depend on family as adults for support services.¹⁴ The Transition Assessment Guideline address individual needs, concerns, goals, and plans for the future. They suggested that their assessment should be used before the individual is ready to leave home, as those with AS adapt slowly to change. Further, they recommended practice with independent living such as encouraging weekend or summer camp opportunities. Finally, the authors noted that parents need emotional support as well.¹⁴

Acceptable outcomes

If one can define a good outcome as a social life and satisfying functioning in school or work, past reports on the outcomes in adult life (e.g., employment of adults with AS) illustrate uneven success. Engstrom and colleagues studied psychosocial functioning of sixteen adults with AS (aged 18–49, mean age 30.8); none was married, none had children, six had partners, and five were living in group-homes.¹⁵ Of the nine individuals with their own apartments, eight

required high levels of support, and only one had a regular job. Most received public support from the state. The overall social adjustment in the group ($N = 14$) was rated as “good” for two cases, “fair” for most ($n = 10$), and “poor” for two cases. A “fair outcome” was as having some social and educational progress. Good outcomes were achievable with sustained social support.¹⁵

Taylor and Selzer¹⁶ surveyed sixty-six adults with ASD to assess their occupational and day activities, as each had left high school within the past 5 years. They found low rates of employment with the majority (56%), spending time in sheltered workshops or day activity centers. They noted that services were inadequate for those with higher functioning ASD. Thus, they concluded that the current service system was inadequate to meet the needs of those with ASD especially those with higher functional abilities, which would include individuals with AS.¹⁶

Twelve males between the ages of 18–21 with AS were compared to a control group of 13 males without AS. Each completed the WHO's Quality of Life measure, the Perceived Support Network Inventory and semi-structured interviews. The researchers found similarities between the two groups for education levels, living arrangements and number of friends. They also identified a preference for solitary activities and less positive employment experiences among the AS group, suggesting challenges for successful transitions to adult life.¹⁷

Howlin and colleagues conducted an 8-year study in the United Kingdom in which participants ($n = 1600$ mean age 31.4 years) had developmental disabilities, including AS.^{18,19} They reported that even though many participants had normal intellectual ability, only 12% were employed. Among the 192 individuals who were hired, 58% were employed in permanent positions and 36% were temporary hires. Most of the jobs were in administrative, technical and computer work, stockroom (52.5%), or clerical/office work (20.5%); and 26% had some college education. Those employed, relied less on government support programs, reported higher satisfaction with life, and were more likely to live independently. These statistics provide evidence that efforts made to increase the probability of successful transitioning might have a measurable, positive social impact. Apparently, there are discrepancies between ideal and the actual transition programs, such that they are not accomplishing the goals of employment and self-sufficiency. One way to explore the apparent mismatch is to examine the perspectives of adolescents engaged in the process of transitioning, their parents, employers, and teachers.

Methods

The phenomenon of transition to community (TC) includes a social process that is jointly constructed by^{20–23} all who are engaged in the process of moving the adolescent out of the insulated social environment of home and high

Download English Version:

<https://daneshyari.com/en/article/4197428>

Download Persian Version:

<https://daneshyari.com/article/4197428>

[Daneshyari.com](https://daneshyari.com)