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What Forms of Living Are Useful and Available for Adults with ASC?

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The typical “launching stage,” in which sons and daughters leave the family home as young adults to live independently, is often altered in families with children with an ASC, as individuals with an ASC often continue to need assistance in daily living into their adulthood. Determining where a person with an ASC will live as an adult is a difficult decision for families. This decision has consequences, not only for the adult with an ASC, but also their parents, siblings, and often other family members. Consideration of the goodness-of-fit for both the adult with an ASC and this broader family system must be taken into account.

Individuals with an ASC often experience “postponed launching” or delayed departure from the family home until well into their adulthood or after parents are deceased. Data from state agencies in New York and Massachusetts in 1998 suggest that about one-quarter to one-third of adults with an ASC in their 30s continue to live with their parents (Seltzer, Krauss, Orsmond, & Vestal, 2000). Thus, long-term family-based living occurs for a marked portion of adults with an ASC, although this rate is lower than the rate of coresidence reported for adults with intellectual disability (ID), due to other types of etiologies (see Seltzer et al., 2000 for discussion of findings).

There are many reasons for continued coresidence of adults with an ASC with their families, including parental preference and worries about the quality of and/or limited availability of appropriate community-based residential services. Parents who continue to have their adult son or daughter with an ASC live with them often highlight the enjoyment that the family derives from the presence of their offspring with an ASC at home and peace of mind that they have in ensuring the well-being of their adult child (Krauss, Seltzer, & Jacobson, 2005). Commonly expressed negative aspects of continued coresidence of adults with an ASC include added strain from caregiving activities and restrictions on the family (e.g., difficulty in spending time away from home and lack of “private couple time”). In addition, families often incur significant out-of-pocket expenses as there is limited financial reimbursement for family-based residential care of adults with ASC.

Adults with an ASC who do not coreside with family generally live in the community, either independently, in supported living settings, in group homes, or with host families. In terms of deciding which community residential setting is most appropriate, there is wide agreement within the field of ID that adults be placed in the most independent and integrated community setting appropriate for their support needs and that the adult is an active participant in determining where they live, who their service providers are, and the type of services received. In line with these goals, there has been a trend away from large institutional settings (16 or more residents) to smaller and more independent residential settings (Prouty, Smith, & Lakin, 2006).

High-functioning adults with an ASC often live independently in their own rented or owned home, either by themselves or with friends, spouses, and/or children. In supported community living settings, adults own or rent their own homes but receive some assistance services, either regularly or intermittently. Supported living services may include helping the adult find or move into a home, supervision of personal finances/budget, support for certain activities of daily living, and assistance in becoming an active member of the community. Group homes, which usually involve 6 or fewer persons with ID living together, are the most common out-of-the-family placement for adults with ID (Prouty et al., 2006). Group homes generally have on-site care staff, who provide supervision and support for activities of daily living, employment, and social and leisure activities. The number of adults with ID residing in a host family arrangement, in which the adult with ID lives with a support person or family, has increased in the last decade (Prouty et al., 2006). A smaller number of adults with ID continue to live in larger private or public institutional settings, nursing homes, or mental health facilities. Residential services are typically operated on a combination of federal and state government funding (e.g., Medicaid in the US), local monies, private pay, and charitable income. Waiting lists for community residential services can be quite long.

The decision for an adult with an ASC to move out of the family home is complex and related to several factors. Out-of-family placement occurs more often when adults have more severe autism symptoms and more severe ID, poorer functional skills, and cooccurring maladaptive behaviors. Circumstances related to the family situation also contribute to placement decisions, including caregiver stressors and burden, parental well-being and health, poor social support networks, and dissolution of the marital relationship. A greater use of formal disability services is also related to out-of-family placement, likely because the use of services decreases family misgivings and worries about the community residential service system.

Common advantages of having an adult with an ASC live away from the family home, as voiced by parents, include having the son or daughter receive better services, get increased opportunities to learn new skills, gain greater independence, and family members having an increased peace of mind and reduced negative feelings of guilt or burden (Baker & Blacher, 2002; Krauss et al., 2005). Mothers whose adult son or daughter with an ASC lives outside of the family home also report having more free time and being less fatigued than mothers of coresiding sons and daughters with an ASC (Krauss et al.,

2005). Recent analyses from the author's longitudinal study of 406 mothers of adolescents and adults with an ASC also indicate that mothers experience a decrease in overall level of anxiety subsequent to their son or daughter moving out of the family home. However, having the adolescent or adult son or daughter move out of the family home was not related to a change in depressive symptoms (Barker et al, in press). Thus, it may be that although the mother's anxiety about her son or daughter's day-to-day activities subsides when the child leaves the family home, there may be an enduring effect of stressful parenting on negative affect. Frequent disadvantages of having an adult with an ASC live away from the family home, as voiced by parents, include feeling unease or guilt about not fulfilling the parent role of providing direct care (Baker & Blacher, 2002) and missing daily contact with the son or daughter and increased worries about their child's future (Krauss et al., 2005).

The transition out of the family home and into community residential settings is often gradual. Parents generally play a central role in this transition. Research indicates that mothers are actively involved in the selection of their son's or daughter's residential placement and are often in regular contact with the residential program in the first few years after the transition into these programs. Thus, even when adults with an ASC are in out-of-family placements, family members continue to remain close with the son or daughter with an ASC.

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