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## Fathers Speak: The Lived Experiences of Fathers of Adolescents with Autism Regarding Transition Planning for their Children

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# FATHERS SPEAK: THE LIVED EXPERIENCES OF FATHERS OF ADOLESCENTS WITH AUTISM REGARDING TRANSITION PLANNING FOR THEIR CHILDREN

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***Abstract:** This phenomenological interview study was an examination of the lived experiences of seven fathers of adolescent sons with autism spectrum disorders as they transitioned out of school and into the postsecondary environment. The study was not created to deal only with fathers of sons; this population was coincidental. The purpose of the study was to gain insight into the fathers' experiences and to determine whether commonalities existed within each father's unique circumstances. A survey was considered, but discounted because of the need for more personal information from the participants. Data were collected through interviews with the participants. Analysis of the transcribed interviews resulted in identification of four emergent themes. The themes identified were: a) ideas and plans for the future; b) thoughts and experiences with the transitioning process; c) school-related thoughts and experiences; and d) communication and interaction with school districts. Participant responses were related to the available research and to the methodological findings of Carl Rogers and John Dewey.*

## Introduction

Many young adults with disabilities move from high school to their next life experiences with few more than the expected stressors such a change involves. However, students diagnosed with autism spectrum disorders (ASDs) and their parents are apprehensive about what the next life circumstances hold and how they will adjust to those circumstances (Black, 1999). For these students and their parents, every change requires meticulous planning, often involving the assistance of doctors, therapists, job coaches, and others who intervene on behalf of these young adults and their families (Konza, 2005). Individuals diagnosed with ASDs often experience communication challenges, behavioral complexities, and social difficulties (Bodfish, 2004), and preparing to enter adulthood becomes crucial as they progress through adolescence (Padilla-Walker, Nelson, Carroll, & Jensen, 2010).

Dewey (1897) posited that learning comes from experience. He consistently argued that because education and learning are social and interactive processes, schools are social institutions through which social reform can and should take place. Schools were important not only as places to gain content knowledge but also as places to learn how to live. Thus, education should revolve not around the acquisition of a predetermined set of skills but around the realization of the student's full potential and ability to use those skills for the student's greater good.

Like Dewey (1897), Rogers believed that students achieve a true education only by putting what they learn into practice (Rogers & Freiberg, 1994). Rogers's (1983) learning theory emphasized two types of knowledge: academic and experiential. Learning by experience was equivalent to personal change and growth. Rogers felt that all human beings had a natural propensity to learn and that learning was facilitated when (a) the student participated completely in the learning process and had control over its nature and direction; (b) learning was primarily based on direct confrontation with practical, social, personal, or research problems; and (c) self-evaluation was the principal method of assessing progress or success (Rogers & Freiberg, 1994). Unlike academic knowledge, students acquire experiential knowledge to meet their needs, usually the completion of an important, real-life task such as maintaining a job or a checking account and learning to drive a car.

While Rogers' experiential learning theory does not specifically address adolescents with ASDs, transference of his theory can be applied. In order for adolescents with ASDs to learn how to develop the skills necessary for successful participation in their communities, they must actually begin to actively participate in their communities (with guidance and support). Significant learning takes place when the subject matter is relevant to the personal interests of the student. In addition, self-initiated learning is the most lasting and pervasive to the student (Rogers & Freiberg,

1994). However, supports must be in place not only to minimize threats to self but also, concurrently, to encourage the student to move into unfamiliar environments.

No advocate is more important to a child with a disability of any type than the child's parents. This does not diminish as the child becomes an adolescent and then a young adult. For young people aged 16–24, transitioning from adolescence to young adulthood involves both predictable and unpredictable changes and challenges in their roles, relationships, and responsibilities (Jivanjee, Kruzich, & Gordon, 2009). Because the parents are very likely to be the primary caretakers/givers for these individuals, preparing them and including them in the transition process is essential; yet indicators such as parents' participation in individualized education plan (IEP) meetings, optional parent-teacher conferences, and back-to-school night meetings, as well as other traditional family involvement indices, have shown that the role of parents in their children's secondary education often diminishes (Harvard Family Research Project, 2007).

Prior research related to family involvement with children with ASDs has included the participation of mothers, of both parents as a unit, of siblings, and of families of young children with ASDs (Dutra, 1999). However, researchers have not addressed the specific role of fathers during the transition process, the effect of the adolescent child's autism on fathers, or fathers' desires for their adolescent and young adult children despite the influence fathers exert on both adolescents and their family units (Parette, Meadan, & Doubet, 2010; Winter, 2005). Instead, fathers have often been treated as afterthoughts (Meyer, 1995; Turbiville & Marquis, 2001). The purpose of this qualitative phenomenological study was to examine via interviews the lived experiences of fathers of adolescent children who have ASDs as their children transition from the secondary school model to adulthood and community life, including college, employment, and independent living. A survey was considered, but discounted because a survey would not allow the researcher to gain the level of personal insight of the fathers who participated as an interview would permit.

## **Methodology**

Three research questions served to guide this qualitative study:

1. What was the father's role in parenting an adolescent child with ASD as the child transitioned to a postsecondary environment?
2. How did fathers of adolescent children with ASD work with their children to prepare them for the transition beyond high school?
3. What was the role of fathers of adolescent children with the formal transition process from high school to the postsecondary environment?

The population for this interview study was fathers of adolescent children diagnosed with an ASD and eligible to receive special education and related services. The children's abilities ranged from students in inclusive environments for the entire school day to students in very restrictive resource center environments. To answer these questions, a convenience sample was selected from a group of fathers living in a midwestern state who were members of an organization that assists with advocacy, service provision, and activities for individuals with intellectual disabilities. To participate, each father had to have a child between the ages of 16 and 21 who had been diagnosed with ASD. The child had to be enrolled in either a public or private secondary school setting and had to be in the process of planning the transition from secondary school to college, trade school, independent or assisted living, work, or any combination of those possibilities. Sixty-three individuals were contacted by email about participating in the interview study. Of that number, nine individuals responded. As the interviewer began to contact fathers for interviews, two of those individuals failed to respond to repeated attempts to contact them prior to the interview process. They were, therefore, eliminated from the sample, leaving an interview study group of seven fathers. The remaining seven fathers gave their informed consent to participate in the study after receiving complete information about the nature of the study. The children of these seven fathers were all adolescent males. The study was not created to exclude daughters; it was coincidental that all the fathers were fathers of sons.

Each father could choose to be interviewed either in person or by telephone or to respond to the same questions in writing. Three fathers participated in in-person interviews; one father agreed to a telephone interview because of scheduling conflicts. Each of these interviews was approximately 30 to 45 minutes in length and was recorded using a digital voice recorder. The remaining three fathers were reluctant to talk directly with the researcher but agreed to answer the interview questions in writing.

The interview protocol consisted of a series of questions regarding the participants' children's educational and transition planning into a post-school environment. The fathers were also asked to discuss their roles in these

aspects of their children's education, including but not limited to their specific inputs and their working relationships with school staff.

Prior to analysis, a professional transcriptionist transcribed the recordings. To determine the validity of responses, selected interviewees participated in member checking by reviewing their responses and confirming the accuracy of those responses in writing or by e-mail.

Analysis consisted of a manual key word and phrase search of the interview transcripts and the written interview responses to identify commonalities. The following key words and phrases were selected based on their use in the interview questions and their relationship to the study topic: *transitioning, testing, college, job training/employment, and living independently*. A description of the participants' attitudes toward the success or lack thereof shown by the schools regarding preparing their sons for transitioning from high school into the adult world was then generated. These data and generalizations were then related to the research questions.

## Results

In addition to forming the basis for answering the three research questions, analysis of the interviews revealed four themes: (a) ideas and plans for the future, (b) thoughts and experiences with the transitioning process, (c) school-related thoughts and experiences, and (d) communication and interactions with school districts.

*Ideas and Plans for the Future.* Six of the seven fathers focused on one or more of these topics: future employment, education, potential living arrangements, and social development. Five (71%) talked about future employment. Two fathers saw their sons working with assistance, even though one later added that his son probably had little chance for employment because of the level of his disability. One father was not sure of his son's future because of the economy, while another hoped his son would have a trade and be "a productive citizen." Two fathers felt their sons' disabilities were great enough to prevent them from being gainfully employed. One of these fathers identified the goal for his son as employment "with minimal assistance . . . from a job coach after much effort . . . to help the employer, co-workers, and our son understand each other and how to work best together, and be utilized on an as needed basis."

Four fathers (57%) discussed future education for their sons. One father saw his son in community college; two noted that college plans were not possible because of the severity of their sons' disabilities. One of these fathers suggested that his son would also "not benefit from . . . most vocational programs." Another father mirrored Rogers's (1983) belief that self-learning takes place when it is relevant to one's personal interests. This father noted options his son had, stating that he "really wants to go to a community college and do computer graphics and photography" but that he also "wants to be a welder." He believed his son could advocate for himself in college, although he'd "ask permission from us to go do it," reiterating that if his son "really wants something, then he'll go and ask."

Four fathers (56%) discussed future living arrangements. Two fathers believed their sons were capable of residing outside their present homes. Another respondent believed independent living was not possible and that his son would continue living at home. The last father who responded on this topic felt that, because of a Medicaid waiver his son had received, it was "possible financially for him to [have] a placement outside our home and receive assistance 24/7/365."

Of the three fathers (43%) who discussed their sons' future social development, two stated that their children needed to continue developing skills appropriate for participation in social activities. The third father detailed the various activities in which his son participated and anticipated that he would continue to be involved in those activities. This father also detailed specific social skills his son would need to be successful after he left high school:

Engaging peers in conversation, although still limited and one-sided. Respecting others, especially adults or authority figures. Sight words and signage . . . demonstrate his mastery of most life skills more when he transitions to living away from home. Communicating what he likes and or wants to do as well as what he doesn't like and doesn't want to do . . . Self-regulating behavior.

Only one of the seven respondents could not discuss his son's future because he was "not a part of his life." However, this father still hoped his child would be successful 10 years from now.

*Thoughts and Experiences with the Transitioning Process.* Six fathers (86%) discussed their thoughts and experiences with the transition process. Five (83%) identified their sources of information about the transition planning process: Three (50%) identified school staff members as their source; one (17%) indicated the school afforded no help in learning about this process and that he conducted personal research to teach himself; and one (17%) identified multiple sources of information, including the state, school and special education teachers and staff, and advocacy agencies.

Of the six fathers responding, two (33%) indicated their thoughts about the transition planning process and their experiences with it were positive, two (33%) indicated they were negative, and two (33%) stated they had both positive and negative thoughts and experiences. Positive thoughts and experiences included believing the transition process was important and that it helped prepare their children for life outside the secondary school model. According to one father, “Through the years of high school, I could see the progression the staff used in scheduling our son into community activities and eventually work sites.” He felt that this was a “standard program tract” used at the school. Although he “appreciated” it in terms of its “structure for planning,” he felt it had “little room for individualized planning.”

Negative thoughts and experiences included lack of support for the transition from high school to community college. One father stated that the school and staff were “poorly trained and poorly aware of Asperger’s or autism.” Even though they provided “all kinds of special activities and coaching and support,” he felt the idea of his son going to community college had never “really ever occurred” to them. Another father lacked confidence in the teachers’ understanding of his son or how to educate him properly. One father believed that job training and challenging curricula, which were not included in his son’s education, should have been. Another father agreed with this sentiment and stated “the school provided little to no support in transitioning.” He specifically identified the need for his son to learn to work “in a group environment,” which was not afforded in his son’s high school career. The fourth father who expressed negative experiences emphasized the “cookie cutter approach” used with the students who attended the program in which his son was enrolled rather than providing transitions plans to meet their “individual needs and interests.” He continued, “We have high goals and expectations for our son, and with our involvement as parents he’ll get opportunities that quite frankly if left to school professionals he might not have.” He believed the school had “limited vision” and relied on the “tried and true” in terms of employment opportunities, the “stereotypical cleaning and shelter workshop type [of] employment/skill set opportunities.” He believed that “someone [i.e., teachers and staff] ought to be able to devote time into individualizing the program for a particular student or types of students and offer any [sic] array of opportunities.” \

*School-related Thoughts and Experiences.* Six fathers (86%) reported their thoughts and experiences concerning school; specific topics included tests and assessments, standard and differentiated diplomas, IEP meeting attendance, and due process. Of the five fathers (83%) who discussed high stakes standardized testing, two reported that testing was essentially inappropriate for their sons. They felt that because of the stress placed on their sons in testing situations, the results were inaccurate reflections of their abilities. One father stated that because his son was required to take the same tests as his nondisabled peers, he had to receive preparation assistance from sources outside the school. However, another father stated that his son was not required to participate in any standardized testing because of the level of his disability. Yet another father suggested that the school may feel “pressure to demonstrate that their efforts are making a difference . . . to show that he is progressing, when in reality . . . he has limited cognitive ability and/or doesn’t/won’t test well.” Because of this, he “question[ed] the validity of the measurement.” He clarified that he was “not saying he can’t learn anything but not always what is measured and what he can learn is difficult to measure/articulate.” He argued for more individually focused assessments, such as an alternate assessment portfolio, an assessment tool appropriate for the 1%–2% of the school population who cannot participate in standardized testing (Lemons, Kloo, Zigmond, Fulmer, & Lupp, 2012).

Six fathers (86%) directed comments toward differentiated diplomas. Three (50%) noted that diplomas are positive markers of success. However, one of these fathers stated that such a diploma would have no practical impact for his son in terms of employment. Another father had mixed feelings about differentiated diplomas; his son had earned a traditional high school diploma:

I would understand why they would want to distinguish between the two. I think it's very important because these kids . . . don't get recognized very much other than maybe [for] some of the trouble they get into because of their frustration of their condition. And so I think it's a minimal expectation, whether it's a diploma or whether it's a certificate of completion, to recognize their achievements, because I will contend that my son, with the challenges he was born with, his accomplishment of making it through the hours and

hours that he and I did homework or he sat with a tutor while other kids were out messing around and getting straight A's is a much more significant accomplishment, and so they need recognition.

One father believed that although the traditional diploma was appropriate for his son, it was not appropriate for all students. Another father whose son had received a differentiated diploma (i.e., a certificate of completion) supported such diplomas:

It means a lot to us, our son, and those who know him that he participated in graduation and was able to participate with his peers, even though his is an attendance certificate. This was and is an important milestone in our son's life. His inclusion in school and community activities is valuable for him and for the community. Our son deserved the recognition of his effort to continue attending school, participating, and for the most part not skipping school and dropping out; [it] was difficult to get him to attend school the final semester.

Six fathers (86%) commented regarding IEP meeting attendance and the participation of their sons. Three (50%) indicated IEP attendance had begun during middle school, earlier than the age of 16 mandated under Individuals with Disabilities Education Improvement Act of 2004 (IDEA). One of these fathers stated that the school administration's involvement regarding his son was solely conducted via IEP meetings. Another father's response mirrored Hasazi, Furney, and Destefano's (1999) findings that many students neither realize that they are designated as disabled nor understand the nature of their disabilities. This father noted his son's lack of interest in attending IEP meetings: "He did not want to be involved. He never liked to be labeled or never liked to think that he was different than any other kid. In fact, he didn't like to even hear much of the feedback."

One father believed attending the IEP meetings was constructive for his son, who had been attending since elementary school: "As he got older, he got more input on what he needed for school." However, another father reflected the opposite: Even though his son had attended every IEP meeting during high school, it had no effect on his programming. Another felt his son's attendance was important because it allowed him "to connect to all of us . . . [involved in] planning his education." Through these meetings he could identify his "strengths and interests and areas of challenge." The meetings also helped him in "connecting . . . the ultimate outcome of an involvement/contribution or vocational contribution to society."

Six of the seven fathers (86%) expressed their thoughts regarding due process. Three (50%) had never filed or even considered filing for due process. One father reported that although he and his wife (a district administrator) had never formally filed, they were very aware of due process. They contacted the special education supervisor to "sort things out" and "got results." Another father also commented on the communication and advocacy efforts he and his wife made to ensure his son received the education they expected him to receive. He indicated these efforts were generally successful, noting that the past summer was the "first time I was disappointed about our son's transition planning." He stated that the school had not followed through with a work experience the father had set up. Although he acknowledged he had not followed up "in writing" with the work site, he had "communicate[d]" with the school. Based on this experience, he planned to "communicate in writing for the fall semester." He also noted that they had previously held their son's schools (i.e., elementary, middle, and high schools) accountable "when appropriate services were not being provided." Because they were aware of their "son's rights and what the school was responsible for providing," they were able to handle most problems "through direct communication . . . [and] the IEP process," and only had to resort "a couple of times" to "written e-mail documentation."

Only one of the fathers had filed for due process after he and his wife were unable "to come to agreement with the high school as far as his [son's] educational needs" were concerned. However, their appeal through due process was unsuccessful. This father believed the process "was a stacked deck . . . [that] state laws support the school system and not the student. It's you against the government; you lose."

*Communication and Interactions.* Only two fathers (29%) detailed communication and interactions concerning their sons' personal lives and school experiences. The first father discussed his son's social interactions, noting that although "he loved to be with other kids," he had "greater relationships with adults." This father noted that even though his son was "a very private person," he had "really meaningful conversations with . . . customers." Because his son could "engage people well . . . his boss recognizes him for that" and has him do "orientations" whenever a customer buys a boat. This father stated that his son has a few close friends, "a small network," but could only identify three, including his girlfriend. The father seemed to attribute his son's small number of friends partially to his ASD in that he wouldn't go to nightclubs or to concerts because the music was too loud and that his son could not "understand why they play it that loud."

The second father described an incident in which his son used an "inappropriate word" in referring to a female student. The father said that his son was "a teenage boy and . . . all teenage boys have feelings." Another girl complained to the principal, who "didn't talk to him [the son] about it." Instead, he "talked to the other girl and her

parents” first. Regardless, he felt his son is “good at being with friends” and that “he’s social,” although “sometimes he gets off track . . . he gets inappropriate.” However, the father believed that was because he was “a teenager, and his hormones haven’t caught up to his level yet.”

*Research Questions.* The fathers’ responses to the interview questions informed the answers to the three research questions that served to guide this study. The first research question concerned the father’s role in parenting an adolescent child with ASD as the child transitions to a postsecondary environment. The interview data indicated that the role of these fathers is no different from that of fathers of children who do not have ASD. However, because their sons were hampered by their inability to self-advocate effectively, these fathers took greater leadership roles in their sons’ transition process, especially when they believed their sons’ schools were not working effectively to meet their children’s needs. They became more aggressive in securing adequate and appropriate transition services, including filing due process when schools were remiss in their responsibilities. As one father stated, “We have high goals and expectations for our son, and with our involvement as parents he’ll get opportunities that quite frankly if left to school professionals he might not have.”

The second research question concerned how fathers of children with ASD work with their children to prepare them for transition beyond high school. The participants indicated that they had to be realistic about what their sons could achieve and what supports they had to ensure were in place for those achievements to occur. Support included the fathers’ use of modeling to prepare their sons for employment after they leave school and their understanding of their children’s ASD diagnosis. They expressed that their work in preparing their children for life beyond high school was mainly to model appropriate behaviors and to support their children with coaching as they transitioned into the adult world. Supports also included tutors, family members, and other individuals within their sons’ schools that enabled these adolescents to attend college or to find suitable employment.

The third research question concerned the role these fathers had within the formal transition process from high school to the postsecondary environment. Again, these fathers saw themselves as advocates, overseers, supporters, defenders, and promoters of their sons becoming self-advocates. They had to possess as much knowledge as possible regarding all aspects of the transition process, especially in those instances in which the schools did not provide the assistance that they should have. Several of the study participants ensured their sons attended IEP meetings to develop their abilities to self-advocate. Even though their sons were not usually active participants, these fathers believed it important for their children to see appropriate behaviors modeled.

Study participants indicated that the schools often failed to communicate appropriately with them regarding their sons’ educational and transition programming. They had to be aggressive in their demands for clear, consistent communication, including voicing concerns to supervisory personnel and instigating due process procedures when necessary. Therefore, another role these fathers assumed during the formal transition process was that of demanding and maintaining open lines of communication with their sons’ schools.

Although each father’s active role in the transition of his son out of the school setting into the adult community was different in its specific details, all the fathers shared one characteristic: They were dedicated to providing whatever assistance and support were necessary to create the most successful transition possible for their sons. During the transition process, these fathers perceived their role to be one of communicating with the school and advocating on behalf of their children. In terms of parenting during the transition process, these fathers perceived their role to be encourager, supporter, and protector. They also perceived themselves to be models of appropriate behavior, coaching their children as they moved from the high school setting into the adult world.

## **Discussion**

With the number of children diagnosed with ASD increasing (Ruiz-Calzada, Pistrang, & Mandy, 2012), preparing these children for adulthood as they progress through adolescence has become an even greater need than it has been in the past (Padilla-Walker et al., 2010). Individual families and society are often faced with the responsibility of absorbing the increasing costs of therapy, specialized education, respite care, and parent training. Given the influence that fathers exert on their adolescent children and on their family units, inclusion of fathers in transition planning is essential.

The fathers in this study answered a variety of questions related to their involvement in the transitioning of their adolescent sons from high school to the postsecondary world. With little information in the literature about the role of fathers of children with ASD, this study may serve as a baseline for examining these fathers’ hopes for their children. The participants’ heartfelt responses to the interview questions were based on their experiences as part of

their sons' everyday lives. Only one father had not been an active participant in his son's life because his son's mother had not allowed him to do so. Still, he expressed his hopes and aspirations for his son's success.

The participants' experiences, reactions, and responses were varied, a mix of positive and negative reactions to aspects of their sons' transitioning experiences. What resonates throughout the study, though, is the genuine caring and concern that each father has for his son and the sincere effort each father puts forth to play an active role in helping his son make this monumental transition. These fathers showed that the roles of fathers with children diagnosed with ASD are the same as those of any father: They are encouragers, supporters, and protectors of their children as they move from one stage in life to the next.

This study revealed several areas practitioners and school districts that provide services to these adolescents should consider including in order to improve the transition process:

1. Increase communication between school personnel and fathers, including more interaction between school departments (i.e., guidance counselors and special education staff).
2. Ensure compliance of transition programs by having local special education administrators oversee the process to ensure all IDEA (2004) requirements are met.
3. Provide continued professional development for school staff regarding the transition process for adolescents with ASD. School staff, especially high school special education teachers, should be trained in how to establish and maintain effective communication with fathers.
4. Ensure that school district personnel are knowledgeable about the community resources available to young adults with autism and work with those agencies to expand opportunities for these adolescents. Such support may include arranging supportive employment opportunities and supportive training for other options than attending college and acting as liaisons to connect fathers to available resources such as Medicaid, counseling services geared toward individuals with autism, and respite care.

The lack of available research on the role of fathers also suggests the need for additional research in the transition of adolescents with ASD from secondary school to the adult world. Such research may include (a) the role of fathers of daughters with ASD; (b) the experiences of custodial single fathers of children with ASD; and (c) the role of fathers in blended families with children with ASD, especially when the diagnosed child is not the father's biological child.

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