Moving Into the World of Employment

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The following is adapted and expanded from original writing by Chris Filler, mother of an adult with autism.

Every three years, the Indiana Resource Center for Autism (IRCA) is legislatively mandated to conduct a needs assessment survey. As part of this survey, families are asked about insurance coverage, Medicaid waivers, impact of educational programs, interactions with the criminal justice system and other relevant topics. The past two surveys have asked families with adults on the autism spectrum who no longer attend school about their employment status.

In 2006, the IRCA survey showed that 61% of people over age 18 represented in the survey were unemployed, 14% worked in sheltered workshops and 25% worked in community jobs. Those who are employed work an average of 21 hours per week and have a median annual income of $6,516. This figure is troubling considering the dramatic increase in the number of people receiving educational services under the eligibility category of autism spectrum disorder (ASD), and the realization that this population soon will be entering the adult service system en masse. It also is troubling because it illustrates the misunderstandings among many professionals concerning the realities and range of ASD.

Families advocating on behalf of a loved one on the spectrum will come to realize that many adult providers have not received current and accurate information on autism. This lack of knowledge will impact eligibility and the types of services the person will receive.

WHAT EVERY ADULT SERVICE PROVIDER NEEDS TO KNOW

1. THOROUGH UNDERSTANDING OF ASD, THE SPECTRUM AND THE DIAGNOSIS IS A MUST.

   It is not unusual for there to be tremendous misunderstandings about Asperger’s Syndrome and people at the “upper” end of the spectrum. Often these individuals are perceived as being willful or manipulative. For those with more significant disabilities, there is a misunderstanding about the potential gifts and talents they may possess. Adult service providers must understand the complexity of ASD, and that there are no generalized services that will work for everyone. They must understand that ASD is neurological and not a mental illness or emotional disorder.

2. PEOPLE WITH ASD REQUIRE A CREATIVE AND CAREFUL ASSESSMENT PROCESS.

   Many people with ASD have unique skills that may not be obvious during a traditional assessment process. They may possess skills suited for a specific “niche” that could lead to successful supported or competitive employment. Identification of these skills often occurs through careful observation, interviews with those who know the person well (e.g., family members or even the individual himself) and a longitudinal assessment process. Just a few hours of traditional assessment or a checklist of vocational skills often misses the person’s unique and most important strengths.

3. THINK ‘OUTSIDE THE BOX.’

   Traditional vocational programs are not always the most appropriate or successful. Vocational/employment programs, support and services all too often are offered in terms of available options, instead of what the person needs and is interested in doing. Due to some people’s narrow focus and need for functional routines, there are situations when all of the available/traditional options for employment are equally unsuccessful. Sadly, there are times when a person is forced into an inappropriate setting and fails miserably. Agencies may then conclude the person is unemployable, rather than searching for a job match that acknowledges skills and talents. Do not assume that a person with ASD who struggles with communication and socialization has that same level of challenge in all areas. In fact, assume the opposite. Many other areas will be significantly more developed than social-communication skills.

4. BE AWARE OF SENSORY PROCESSING CHALLENGES.

   These challenges often limit people with ASD if gone unrecognized and unaccommodated. The person’s perception and ability to tolerate or cope with the sights and sounds of a typical work environment can be quite different than that of their co-workers. Accommodations can be made and coping skills can be developed. However, this does not happen automatically, quickly or under threat of losing a job. In fact, the person likely will shut down or quit rather than deal with the situation or attempt to explain the difficulties. This does not mean that the environment needs to be silent or rigid. It means, however, that opportunities to
periodically leave a stressful environment should be available and without consequence. Environmental control or accommodation can dramatically change the quality and quantity of the work or product, while presenting the person in the most positive light.

5. BUILD ON STRENGTHS. This should be the philosophy when working with any one. However, the strengths of those with ASD may be less obvious and more narrowly focused than for others who come to the attention of employment service agencies. Rather than addressing deficits, adult service providers should acknowledge strengths and interests.

6. PREPARE, PREPARE, PREPARE. Be certain the person understands what will happen during the assessment and at work-site trials, as well as the work-training processes. Some require visual supports. Others may need to visit and explore the environment. In some cases, a verbal description and explanation of the situation, schedule and expectation may be sufficient. However, always err on the side of concrete and visual supports.

7. COMMUNICATION SHOULD NOT BE ALL TALK. Using fewer words often is better. People have a tendency to talk too much to folks on the spectrum, regardless of whether the person is verbal or not. They assume that a verbal person will be able to understand verbal expression as well as other employers. This is misleading, as some with ASD may use many words, but have limited receptive language. Be prepared to use more written and concrete communication and directions. Develop schedules, visual sequences of tasks and information about the written and unwritten “rules” of the work culture. Employers and co-workers should be aware that the words they say may not communicate meaning as much as environmental reminders and cues. And finally, realize that many of these individuals do not understand sarcasm, innuendos and double meanings. As a result, the directions may be confusing or meaningless.

8. CAREFULLY CONSIDER THE ENVIRONMENT AND PREDICTABILITY OF THE JOB. Workshop-type settings often are the worst for those on the spectrum. These settings typically have many people, loud noises and a lack of privacy or place to get away. Even the person that seems less capable may perform better in a community setting with support than in a sheltered setting. Intermittent employment may not be a good idea, either. Seasonal, ever-changing jobs increase the likelihood of anxiety, stress and behavioral escalation. This does not mean the person should be placed in a boring or static situation. This means that predictability and stability of the employment will go a long way toward creating an efficient and successful employee. If the job offers change, use environmental and organizational support to create predictability and structure.

9. SOCIAL EXPECTATIONS REQUIRE INSTRUCTION. Social challenges are a hallmark of the ASD diagnosis. These challenges extend beyond the school years and can dramatically affect the person’s ability to successfully integrate into a work setting. Be prepared to help the person understand the social expectations (rules) of the job. These often are unwritten or hidden rules of the work culture, and can be critical for acceptance. Do not assume the person will “read” the social climate and adjust. It will not happen. Instead, prepare the person by teaching expectations. Rehearse how to greet people, ask for help, engage in small talk and accept (or give) compliments. The employer should be aware that if social errors occur on the job, they should be address calmly and directly. Subtle suggestions will not work.

10. SYSTEMS MUST WORK TOGETHER (DELAYS CAN BE DEADLY). The traditional “hand-off” between school and adult services over a few weeks or even several months often ends in delays in service or employment, misunderstandings and even failure in achieving a successful outcome. Agencies must work with schools to identify students early, begin to actively work with the school team to get to know the student, and begin to identify adult services and potential employment. Timelines vary from state to state and agency to agency. Funding and eligibility requirements may get in the way of a smooth transition. In fact, funding will always be an issue. However, agencies must begin to create opportunities to work together systematically so that the transition is seamless, or at least does not unravel all together.

One, final thought for parents: As your son or daughter moves from the public school system, which has clear legislative entitlements, to the adult world of eligibility, it is important to have a vision for your child. Examine the possibilities. This issue of the Autism Advocate highlights stories of success that occurred because family members pushed the system and expected a different type of future for their child. Hopefully, these exceptional stories will become common occurrences someday.

ABOUT THE AUTHOR
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