Adult Autism & Employment

A Guide for Vocational Rehabilitation Professionals

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Introduction

● *Introduction for Vocational Rehabilitation Professionals*

This guide is an outgrowth of another book, the Handbook of Disabilities (available online at www.dps.missouri.edu). It grew out of a growing awareness of the limitations of the previous handbook entry on Autism and Autism Spectrum Disorders (ASD). The updated entry soon grew too large for the handbook and became this report.

Although there is an extensive literature on the characteristics and support needs for school-aged children with ASD, to date there is almost no research literature on adults with ASD. What literature exists is almost entirely focused upon "High Functioning Autism" or based on speculative extrapolation of the literature for school-aged children. This guide is an attempt to address this deficit.

Many of the insights and suggestions in this guide come directly from James Emmet. In my opinion, Mr. Emmet is the most experienced person in the U.S. on providing employment supports to adults with ASD. He combines a strong background in public Vocational Rehabilitation (VR) with strong ties to the business community and ASD community. Since 1996, Mr. Emmet has directed several employment initiatives in the Chicago area for people with ASD. In 2005, Walgreens hired Mr. Emmet as project manager to develop their innovative ASD employment outreach program at their South Carolina regional distribution center. Since then he has gone on to consult with a number of national businesses on similar ASD employment outreach projects. Much of the information he has provided for this guide is completely new to the vocational rehabilitation literature on ASD.

During the research for this guide, two issues emerged which are of major significance to vocational rehabilitation.

The first emergent issue is that many traditional vocational rehabilitation practices are not only ineffective for people with ASD, but actively distressing to them. This frequently leads to clients withdrawing from the VR process. One state VR agency recently documented a 90% drop-out rate for VR clients with ASD, most of whom never got past the vocational evaluation. In addition, there are significant issues with the use of job coaches and job training. These are addressed in more detail later in this report.

The second emergent issue is the remarkable diversity of the ASD population. The individual features of ASD are not more "significant" than those of many other disabilities served by vocational rehabilitation professionals on a routine basis. However, the range of potential features among this population is remarkable. Nearly every one of the handful of articles on employment of adults with ASD comments on this diversity and on the challenge it presents to Vocational Rehabilitation, but few articles provide any suggestions more specific than "match the job to the client". In addition, because there is such a constellation of diverse, potential features, the DSM criteria must focus solely on those few core features that are consistent across the ASD population. This means that the diagnosis of ASD provides almost no information for vocational rehabilitation professionals about the potential features of clients with ASD.

This report makes an initial attempt to describe this diversity and provide concrete suggestions for the potential features. Unfortunately, the large number of possible features result in long lists of, for example, possible interview questions, interview accommodations, work place accommodations, etc.

Our staff at the Disability Policy & Studies office at the University of Missouri has been impressed with the determination of numerous state VR agencies across the country to actively work on this topic. We believe there are significant and positive changes beginning to happen and we are excited to be a part of the process.

● *Introduction for ASD Parents, Advocates, and Activists*

Although I hope this guide will be useful to you, you are not the primary audience. This book is written for vocational rehabilitation professionals and employment services providers – the people whose job it is to find jobs for people with disabilities. This guide contains a lot of detailed information about how the features of people with ASD and the needs of the workplace interact, with suggestions about addressing common challenges from those interactions. But it does NOT contain some information you may be expecting.

In particular:

➢ **There is no discussion of when or if employment is appropriate**. Vocational Rehabilitation begins with the basic principle that ALL people with disabilities can and should work. What's more, they should work in "normal" jobs out in the community ("competitive employment" in voc rehab language), earning pay and benefits comparable to everyone else. This guide assumes that any person with ASD can work and wants to work, and starts from there.

➢ **There is no discussion of how to get employment services.** This guide is for the professionals who provide those services, not for the clients who are seeking the services. There are plenty of other resources available which describe how to contact your state and local vocational rehabilitation agency and apply for services, and which describe the steps of the vocational rehabilitation process. If the person with ASD is still in high school, their counselors and support staff should already be in touch with local Vocational Rehabilitation staff in preparation for "transition" (in voc rehab language) from school to work. If that is not happening, you should discuss the topic with them or contact the local Vocational Rehabilitation agency yourself.

➢ **There is no discussion of how to find jobs.** Finding a job is, of course, a primary goal of vocational rehabilitation services. However, that process (called "job placement" or "job development" in voc rehab language) is what vocational rehabilitation counselors and employment service providers already do – it is what they have been trained for. Topics such as "How to suggest an employer hire a person with a disability" and "When to disclose a person's disability" should already be familiar to vocational rehabilitation professionals and providers. This guide is about the specific adjustments that vocational

rehabilitation professionals need to make to their standard services so those services will be most effective for clients with ASD. There are many excellent resources available elsewhere about job placement and job development, which you can locate if you need that information. We would particularly recommend *The Job Developer's Handbook: Practical Tactics for Customized Employment,* by Griffin, Hammis, & Geary.

➢ **There is no discussion of how to get a diagnosis or medical treatment**. Vocational Rehabilitation counselors do not diagnose or determine medical treatment for any disability. Part of the application process for Vocational Rehabilitation services is determination that there is already a diagnosis of a disability. If you are wondering if someone has ASD, this guide will not help you.

What you can expect to find in this guide is a discussion of the aspects of ASD, specifically, that can impact a person's job performance and how the job and work environment can be adjusted to accommodate.

Contents

Description of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are a group of neurologically-based developmental disorders which affect a person's thinking, perception, attention, social skills, and behavior. The term ASD is relatively new and covers several disorders which the DSM groups under Pervasive Developmental Disorders. The two main (and best defined) disorders are Autism (or Autistic Disorder, in DSM terminology) and Asperger's Disorder. Pervasive Developmental Disorder- Not Otherwise Specified – a catchall term for atypical conditions – is the most common diagnosis of ASD/PDD.

The features of autism, in particular, usually show up around age one or two and are present for life. Other disorders may show up slightly later in childhood. ASD is not degenerative and some features may improve or change with age and training.

The term "Spectrum" in the name indicates the wide variety in characteristics that may be experienced by different individuals with the same ASD diagnosis. An autism/PDD diagnosis actually tells you very little about a person, since so many features can vary (see below). *(Note: in this document, ASD is used as a broader term than autism, encompassing individuals who may have significant autism features but do not meet the specific diagnostic criteria. The term autism is reserved for the specific diagnosis or to reflect the language of specific research articles.)*

A person with ASD is sometimes referred to as being "on the spectrum."

Researchers are not certain what causes ASD, although the primary suspects are genetic and environmental factors, with most evidence pointing to complex genetics (see further discussion below). There is debate about whether ASD is a single disorder with a lot of variable symptoms or a set of related, distinct disorders with a core set of overlapping symptoms *(Jensen & Sinclaire, 2002).*

● *Features*

➲ Diagnostic Description

Autism is the more common of the two well-defined ASD diagnoses and acts as a standard model for ASD. There are three main elements to the diagnostic criteria for autism in the DSM: impaired "reciprocal" social skills (sharing, friendships, conversations, etc.), impaired communication skills (deficits in one modality with little interest in alternative strategies), and unusual, repetitive behavior or unusual interests.

In recent decades there has been a dramatic increase in the number of children receiving an autism diagnoses. At least some of this increase is probably caused by changes in these diagnostic criteria. Since the 1960s, the diagnostic criteria for autism have been revised and widened about every ten years as the DSM was updated. Some people feel

the changing criteria and increased awareness account for all of the increases in rates. They believe the number of children with autism has always been high, we just have not realized it before. Others feel those factors do not completely account for all in the increase and there is a genuine rise in the number of children with autism. They suspect there are environmental factors interacting with genetic factors to cause the increase, but no one knows exactly what those environmental and genetic factors are. Some statisticians say the changes in diagnostic criteria confuse the research data so much that they cannot tell one way or the other if an actual increase is happening *(Hollenbeck, 2004; Fombonne, 2005; Hertz-Picciotto & Delwiche 2009).*

There is no data on the number of adults with ASD/autism.

It is important to understand that the diagnostic criteria for autism are not very helpful to vocational rehabilitation professionals. The diversity of people with ASD/autism is so great that the diagnostic criteria must focus narrowly on a weighted checklist of a small number of core features. The criteria do not mention the many other significant features commonly associated with ASD/autism, they do not give any intuitive feeling for how these features are associated with each other, and they do not give any hint of the enormous variation possible among people with ASD. For these reasons, the diagnostic criteria do not give vocational rehabilitation service providers useful profiles about a particular individual with ASD or the ASD/autism population in general.

➲ Experiential Description

One researcher *(Olney, 2000)* has sifted through autobiographical accounts of autism and found some common themes about living with autism. These provide an initial glimpse of what people with ASD/autism might be experiencing and how the features might be related with each other.

➢ **Sensation** – people with autism often report having "altered" sensitivities to sound, touch, vision, smell, taste, and movement – which means their perception of the world through one or more of these senses may be increased, decreased, fragmented, variable, or just confusing. One person remembered that, as a child, she would look at other people and only see disconnected pieces, not whole people. Some people with autism report trouble processing more than one sense at a time. Others have trouble filtering out background sounds, sights, etc. and get easily distracted or annoyed by things that do not bother other people. A few report acute panic attacks when overwhelmed by confusing sensations.

➢ **Attention** – people with autism often report difficulty paying attention to more than one sensation at a time. If they are listening to something, for example, they may not process what they are seeing while listening. This is also described as difficulty in rapidly shifting their attention from one sense to another. On the other hand, this can give the person an ability to focus intensely on one activity or skill and exclude everything else, leading to strong abilities on skills requiring concentration or practice.

➢ **Emotion** – people with autism report that anxiety and distress are common for them. They frequently struggle to interpret events and situations, process sensory

information, or filter out distractions. To people around them, the person with autism may seem to overreact tremendously to minor frustrations or situations. On the other hand, their altered sensations often give them great pleasure from situations and objects that do not appeal to others.

- **Communication** – Communication is a challenge for everyone with autism. Even people who are labeled "high functioning" report significant struggles with communication. In conversations with others, they have difficulty understanding implications, understanding context, or separating essential parts from trivial ones.

- **Time and Place** – People with autism sometimes report problems orienting themselves in time or knowing what is coming next. As with sensory issues, their sense of time and place may be fragmented or decreased. This can make them lose track of the "why" of a situation or become very anxious when having to wait, change plans, or transition to new activities. They can more easily anchor themselves during ongoing familiar activities and familiar routines.

- **Coping Strategies -** Most people with autism find ways to calm themselves and to cope with the features of autism they experience. These include:

- **Rituals, Repetition, and Rhythm** – These are nearly universal among people with autism (and part of the diagnostic criteria). They include rhythmic movements, rocking, hand flapping, humming, walking, and other repetitive actions. For many people with autism, these are soothing and help them cope with hypersensitivity. Others find the activities clear their heads and help them think.

- **Compulsions** – Some people with autism report that obsessions and compulsions about, for example, schedules or sorting help them deal with anxiety, including confusion about time and place.

➲ Functional Description

One expert who works with adults with ASD in job settings describes additional features that cluster together within the ASD spectrum. These features are not part of any official definition of autism or ASD, but they provide a useful framework for understanding the possible characteristics to expect of individuals with ASD (*adapted from Emmett, 2004, and Emmett, personal communication, 2009*).

It is important to note that **any individual can show any combination of states on the various features below**.

❖ Cognition

> **Measured I.Q:**
> People with ASD may be of average, above average, or below average intelligence (aside from questions of how intelligence is measured and the impact other ASD features might have on that measurement). Some researchers use the term "High Functioning Autism" for individuals who experience autistic symptoms but do not experience mental retardation. However, high functioning autism is not part of the DSM classification and has no standardized definition. Individuals with Asperger's Disorder tend to rank

relatively high on IQ. Even individuals with above average intelligence and ASD will almost always still have trouble understanding some aspects of language and social communication and experience other features of ASD.

➢ **Concrete Thought**:

People with ASD often think concretely rather than abstractly, and may process the world in a narrow, intense, detailed manner. They may have trouble following complex instructions and will probably learn better from demonstrations, visual examples, or diagrams.

Concrete thinking can make it difficult for some people with ASD to understand why they are asked to do or learn something. They may understand the steps of a task, for instance, but may have difficulty connecting those steps to the final goal. Tasks can become isolated, confusing events with no context unless coworkers or trainers help them understand the larger picture. Or they may be able to recite lines from songs or poems without understanding the overall message of the piece. They can also have difficulty summarizing information.

➢ **Attention to Detail:**

The tendency toward concrete thinking can give some people with ASD a strong focus on detail. They may notice books that are out of order on a shelf, changes in how things are arranged on a desk, or parts of a printed pattern that do not fit properly. Research studies show that this is not a "cognitive deficit" but a style of thinking – something the person can change with effort, but the way they tend to function if they do not need to change *(Happe & Frith, 2006)*. This ability makes some people with ASD very good at detail-oriented tasks.

➢ **Difficulty Planning and Sequencing**:

The tendency for concrete thought and focus on details can lead to problems with planning and understanding sequences. Planning requires that a person focus on both the final goal and the intermediate steps at the same time, which can be a major challenge. Similarly, deciding on the best order or sequence in which to perform particular steps of new tasks may be challenging. For example, a person may know how to put on shoes and how to put on socks, but they may put on the shoes first instead of second.

➢ **Fixation:**

Many people with ASD have a favorite topic or activity on which they fixate. They are very motivated to experience, learn, and think about their topic and, if they have verbal skills, will often talk at length about it, monopolizing conversations. Some people with ASD are drawn to orderly systems, such as computers, sorting activities, or particular types of machines (for example, dishwashers or vending machines), which often determines the topic they fixate upon. Their knowledge about the topic or activity may be remarkably deep, but it is probably very narrow. They also may not realize that other people do not have the same interest or depth of knowledge.

Alternatively, someone with ASD may fixate on rhyming words, counting, or lists of items. If they are nonverbal, they may fixate on feeling textures, repeating complex rituals, or rocking back and forth. In some ways, this fixation can resemble obsessive-compulsive disorder and may have similar self-soothing functions.

These fixations may be challenging or confusing for coworkers and supervisors in a job setting. However, if instructions, tasks, or duties can be framed to match the person's natural fixations, those fixations can become very functional.

➢ **World View:**
People with ASD may mentally organize/categorize their world in ways which are very distinctive. If a person has a fixation, he or she may frame up places, objects, etc. in relation to that fixation. For example, each object in a room may be associated with a different pop music song and sorted by the year its song was recorded. Or rooms may be sequenced based on the number and type of light bulbs in each. In addition, common ways that we organize the world may not make sense to a person with an ASD. For example, hotel rooms numbered with the floor number followed by a room number (904 – 9th floor, 4th room) may be confusing – there are not, in fact, that many rooms in the hotel.

❖ Communication, Two-way Interactions

➢ **Expressive Language** (speaking, communicating to others):
Some individuals with ASD have extensive, impressive vocabularies and others have few verbal skills at all. In the last few decades there have been increased, intensive interventions for children with ASD, dramatically improving their communication skills, but there are still people with ASD who do not have verbal language. Many people with ASD, even those with strong verbal skills, also have behavioral ways of expressing emotions, but the specific meaning of a particular behavior is individualized. It is always important to learn the behavioral language of each person with ASD and share this information with co-workers and employers.

Some people with ASD exhibit echolalia: the repeating back of words, phrases, or passages from someone else. These may be repetition of what was just said ("immediate echolalia") or repetition of something from a movie, album, or other media from days, months, or years before ("delayed echolalia"). These are usually a type of behavioral language and it is important to learn what the behavior means to that person.

➢ **Receptive Language** (hearing, understanding others):
Most people with ASD process visual information better than verbal information, even those with strong expressive and receptive skills. During meetings with a counselor or support person, they may need occasional periods of silence to process new verbal information. It may also take them a while to

respond to questions or make decisions. Visual information and supplements (diagrams, color coding, symbols, written outlines, etc.) are always helpful. Some basic sign language skills may also be helpful for counselors, coworkers, and friends. Many people with ASD know sign language and find it easier to process verbal instructions when there are accompanying signs, even if the signs are very basic.

People with ASD tend to hear language very literally. So phrases such as 'Save your breath' or 'Keep it under your hat" can confuse them. This literal mindedness can also cause resentment in the person with ASD toward others, since they may interpret a casual agreement as a firm promise or interpret a "rule of thumb" as a firm regulation. When others do not live up to these literal interpretations, the person may feel betrayed or decide the others are untrustworthy.

➢ **Social Interaction:**

The ability to socially interact with others can vary tremendously among people with ASD. Some people with ASD seem to be lost in their own internal world (although they are actually quite aware of their surroundings), or minimally interactive. Many simply are not that interested in social interaction and friendships. Others may be very outgoing but still have trouble decoding social situations and selecting appropriate responses.

People with ASD often have trouble interpreting the social signals of language – tone of voice, figures of speech, humor, sarcasm, etc. In conversations, they may have difficulty reading cues from other people about taking turns speaking or about changing to a new subject. Nearly everyone with ASD benefits from some level of support and coaching on social skills.

➢ **Eye Contact**

It is worth noting that many people with ASD have difficulty making eye contact with others during conversations. This is not a sign of inattention, shyness, defiance, or other emotion. For most people without ASD, making eye contact is an important part of receiving nonverbal social cues, but people with ASD generally struggle with social cues and do not find eye contact useful or comfortable. There is some evidence that people with ASD can have trouble listening and performing "looking tasks" at the same time, so eye contact may make it harder for the person to process a conversation. Avoiding eye contact may be a coping skill for sensory processing issues.

➢ **Expressing Emotions:**

People with ASD often have trouble interpreting and expressing their own emotions. To others, some people with ASD may appear to have a "flat affect" – show no facial expressions – although others with ASD may show emotions quite well but still have trouble verbalizing feelings to themselves and others. Those with reduced or flat affect will often use "odd" behavior to express feelings they cannot verbalize. Hooting, flapping of hands, rocking back and forth, and similar behavior is often an attempt to communicate. It is important

to understand the behavioral/emotional language of the individual. It is also useful to provide coaching on how to ask for help in dealing with frustration, anxiety, or other emotions. If troubling emotions build up, instead of being addressed, the emotions may eventually erupt as a temper tantrum and the person might lash out at people or objects.

> **Understanding Others:**
>
> People with ASD may have trouble recognizing what emotions other people are feeling. Researchers use the term "**Theory of Mind**" to describe our ability to predict/imagine/understand what other people are thinking or feeling – seeing things from the perspective of others. There is evidence that people with ASD have trouble achieving a theory of mind and some may lack it entirely. This may be linked to deficits in social skills and language skills. One researcher has called this "Mindblindness" *(Reynhout & Carter, 2006; Garfield, Peterson, & Perry, 2001).*
>
> Not surprisingly, this can affect communication skills. For example, children with ASD often do not point or gesture. This theory suggests they cannot understand that others do not see the same things they are looking at. Adults with ASD may have difficulty understanding that other people do not know or feel the same things they do. Similarly, if a person with ASD asks a question and other people do not understand it, the person may not be able to figure out how to rephrase the question and will, instead, just repeat the same question over and over. This does not mean people with ASD do not care about others; they may just be unable to step outside themselves and see the point of view of others.

❖ Sensory Issues

> **Hypersensitivity:**
>
> It is very common for individuals with ASD to be "hypersensitive" in one or more senses. These can include sensitivity to light (including sensitivity to the nearly invisible flicker of fluorescent lights), sounds (background noises become distracting), touch (the feel of fabrics, surfaces), smell, and taste. These sensory issues can make a person with ASD easily distracted, challenging their concentration. Noisy, cluttered, brightly lit, or busy environments can be very challenging for them.

> **Hyposensitivity:**
>
> A few people with ASD are remarkably insensitive to certain sensory cues – for example, failing to notice a fire alarm or flashing lights. In some cases, people with ASD may seek stimulation of these senses, such as excessive licking or staring at objects of interest. In other cases, they may not respond to environmental signals like a ringing phone or honking horn. Some individuals find "deep pressure" comforting and may wear weighted vests or wrap themselves tightly in a blanket (Emmett, 2009; Kurtz & Collins, 2009).

❖ Behavior

➢ Adherence to Routines:

Most individuals with ASD value routine highly and try quickly to establish a routine in any new environment. Some value routine so much they become upset at the least change and need prominent, advance warning of changes. Others simply find routine comforting. Some routines become so rigid they resemble obsessive-compulsive disorder.

However, individuals with ASD can also become bored with endless repetition, so some level of variety, control, or flexibility within a routine framework is helpful.

Some people with ASD also prefer orderly environments and will feel a strong urge to line up or straighten objects in messy situations. A person with ASD may become very distracted if objects have been moved from their usual place or an area seems cluttered.

➢ Prompt Dependence and Generalization:

As discussed above, people with ASD often start to create a new routine as soon as they enter a new environment, such as a work site. If there are verbal or visual prompts/reminders available, they will often anchor their routine on those prompts. If the prompts are removed, their routine falls apart and they become confused, anxious, and frustrated. In a work or training situation, it is a bad idea to have initial prompts and try to phase them out later. It is also a bad idea to teach the person a task in one situation/environment and ask them to perform the task in a different situation. Training should be done in the final work environment and with its prompts.

➢ Gross Motor Skills:

Many people with ASD have trouble with gross motor skills. This may be mild, leading to clumsiness, or significant, leading to difficulty walking or an unusual gait. This may be rooted in a problem with body awareness, or proprioception – the understanding of where your body is in relation to things around you. A person may tend to knock things over, bump in to things, or have trouble navigating through close quarters.

➢ Fine Motor Skills:

Many people with ASD have trouble with fine motor skills. This trait is not related to possible gross motor skills – the two may or may not occur together. People with fine motor skill problems may have trouble grasping small objects, writing (many prefer to type), buttoning clothes, and drinking from a glass. Problems with fine motor skills may also cause difficulty with the mechanics of speech, independent of their cognitive or social skills.

● *Popular Stereotypes of ASD Features*

➢ **Genius Skills**:
> In books and movies, people with ASDs/autism often have one or two narrow areas in which they are geniuses even though they struggle with basic social and cognitive skills. In reality, only a few people with ASD experience such **"savant" (or "idiot savant") skills**, but most people with ASD do not. However, many have a "mild" version of this called "splinter skills", in which they have remarkable memory for certain facts, numbers, or musical themes. And these skills are not unique to persons with ASD – at least half of the people with these skills have some other cognitive or neurological disability, not ASD *(Treffert, 2006)*.
>
> The rare individuals with true savant ability show remarkable skills in some narrowly focused area, such as drawing, mathematics, music, or memory. Typically, the person shows amazing mastery of detail but does not seem to get the big picture. In drawing, for example, some people with savant skills can draw detailed human figures from memory, but while making the drawing they will move from drawing one area in detail to drawing another in detail. In contrast, typical artists will draw the overall outline and proportions of the figure first, then fill in the details. Similarly, individuals with the "calendar skill" may be able to tell what day of the week any date in history fell, but not be able to relate those dates to the larger story of history. Some researchers have proposed a "weak central coherence theory" which proposes that these individuals are missing certain "cognitive filters" in the mind which, for the rest of us, blur details together during sensory processing, but which help us see the whole picture *(Happe & Frith, 2006)*. In effect, people with these savant skills may have more direct access to their raw sensory data, allowing them to find and manipulate details more easily but at the cost of the big picture. However, this theory does not explain the remarkable memory skills that usually accompany savant skills *(Treffert, 2006)*.

➢ **Repetitive Behavior:**
> Another common stereotype about people with ASD/autism is that they often perform meaningless repetition of some activity, such as rolling a plate on the floor, repeating a phrase, flapping their hands, or rocking back and forth, and are oblivious to the world around them. Medical researchers call these behaviors "Stereotypies" – repetitive, almost mechanical, movements, postures, words or phrases that are associated with certain disabilities (Schizophrenia, Tardive Dyskinesia, etc.). Not all people with ASD experience stereotypies, but some do. For some individuals, these behaviors seem to be a way to calm down or block out uncomfortable sensations. For others, the stereotypies are a personal expression of their emotions, and understanding the meaning a particular motion has for a person can be a huge help to communication. In general, people experiencing stereotypies are aware of the world around them, even though they seem to be ignoring everything. Unless the stereotypies are actively disruptive, it is best to accommodate them in the work place and try to understand them as a type of communication. A very few individuals experience self-harming stereotypies, such

as picking the skin, biting themselves, banging their head, or pulling their own hair. These, too, may be a type of communication or may be a sign of a medical issue (see below).

● *Aggressive or Challenging Behavior*

Some, but not all, persons with ASD exhibit **Challenging Behavior** on occasion. The term Challenging Behavior covers a wide range of things, including **Self-Injurious Behavior (SIB)**, aggression towards others, damage to property, inappropriate sexual behavior, and constant screaming, among other things. There is very little research on this topic and much concern about stigmatizing particular individuals as "problems", but it deserves some attention in planning for employment and independent living.

There are several possible causes of challenging behavior (see below), but there is no research information on which causes are most common or likely. The best way to deal with challenging behaviors is to monitor the behaviors closely, conduct a functional analysis to identify any contributing or associated factors (time of day, time of month, setting, recent activities, events immediately before, events immediately after, etc.), and then review the possible causes for a likely match.

➲ Contingency Plan

If a person has no current challenging behaviors but does have a history of them (particularly aggression toward others), and if they are in a work situation, it might be useful to talk about a contingency plan with supervisors or coworkers. This plan would cover what to do and whom to contact if the behavior ever happened again.

The problem with making a contingency plan is that it could easily stigmatize the person in the minds of coworkers. It will be important to make sure supervisors and coworkers know that the behavior may never happen again. The behavior should be described as an unusual, unlikely event – a way for the person to express something that they can't express in any other way; and something that is not part of the persons' normal behavior. Supervisors and coworkers should also understand that the person knows the behavior is inappropriate and does not want to do it. If the behavior occurs again, it is because the person is experiencing something significant and needs some help.

➲ Possible Causes of Challenging Behavior

➢ **Communication**

Even people with strong communication skills may sometimes have difficulty expressing things in words and resort to behavioral communication.

- **Frustration with a situation** – the person may not like an activity, may need something (a tool, a drink of water, a bathroom break, help with something), or may be worried about something.

- **Confusion about new aspects of a situation** – the person may not understand the instructions being given to them, changes in a routine, a new situation or activity, changes in the environment, or what others are doing.

- **Confusion about goal, purpose, or sequence of activity** – the person may be confused about why they are supposed to do something or about what comes next in the sequence. Even individuals who normally are clear and "anchored" about their regular routine may have an occasional bad day when they don't feel well, and lose track of the purpose or sequence of activities. They may become confused and frustrated. If clear, graphic guides are available in the work space, they can reorient themselves.

- **Over-stimulation** – the person may be upset about too many new things, new activities, or new people in the environment.

- **Under-stimulation** – the person may be bored, may be attracted to certain kinds of stimulation (certain lights, certain sounds, certain textures), or may find certain actions soothing. This can lead to self-stimulating behaviors or self-injuring behaviors, such as licking things, shouting loudly, or pulling his or her own hair.

  o *What to look for –*
    pay close attention to recent events, actions of others, and settings of the behavior. Notice if the behaviors increase or decrease when the person is engaged in particular activities. Also consider changes in home situations and whether the person is getting some benefit from the behavior.

  o *What to do –*
    the most common approaches for these type of behaviors are "functional communication training" (teaching the person more appropriate ways to communicate their message) and behavior modification techniques (*Matson et al, 2005).* Accommodations might also be useful.

➢ Physical/Neurological Issues

- **Gastrointestinal pain** – the person may be experiencing cramps from diarrhea, constipation, or general intestinal problems. There is a higher incidence of GI problems among people with ASD *(Myers & Johnson, 2007).* It is worth asking about their bowel movements and diet.

- **Lack of sleep** – the person may be tired and irritable. There is a higher incidence of sleep disruption among people with ASD *(Myers & Johnson, 2007; Polimeni et al., 2005).*

- **Hyper-sensitivity** – the person may find certain kinds of light, sound, or other stimuli very uncomfortable and distracting. These sensitivities are common among people with ASD.

- **Migraine** – the person may be experiencing pain and distraction from migraines. There is no evidence of increased incidence of migraines among people with ASD, but migraines are common enough in the general population to consider for people with ASD.

- **Pain** – there may be other typical medical issues causing the person pain, including dental problems.

- **Seizures** – individuals showing self-injuring behaviors or periods of being non-responsive may be experiencing seizures.

- **Side Effects** – some research says that more than half of all people with ASD are taking some sort of psychotropic medicine. These medicines can have serious side effects, including nausea, drowsiness/sedation, abdominal pain, fatigue, headaches, and general agitation, among other things. It is worth consulting with the person's doctor or medical professional about what medications they are taking.

  o *What to look for* –
    pay close attention to the person's actions just before and just after the behaviors for signs of pain or distraction. Ask about family medical history and current medications. Issues such as seizures and migraines may be associated with particular settings or activities or may appear random. For seizures, look for confusion and sluggishness after the behaviors.

  o *What to do* –
    contact a doctor (or other medical professional) for an examination and treatment.

➢ Psychiatric Issues

- **Depression** – people with ASD have increased rates of depression and bi-polar depression.

- **Attention Deficit / Hyperactivity** – the DSM IV does not allow a dual diagnosis of ADHD and ASD, but there is anecdotal evidence of ADHD in people with ASD (*Swedo, 2008*).

- **Anxiety Disorders** – as discussed in the experiential description earlier, individuals with ASD may experience a lot of anxiety from sensory issues, communication issues, and cognition issues. In some cases, the anxiety might become pervasive and require psychiatric treatment.

- **Aggressive Urges** – a few people with ASD have aggressive urges, emotional outbursts, or extreme self-injuring behavior which they cannot control. The FDA has approved one particular anti-psychotic medication for reducing these behaviors in people with ASD *(Myers & Johnson, 2007).* This does NOT mean these people are experiencing psychosis or schizophrenia, however. This approach should only be used after other strategies have failed.

  o *What to look for* –
    these explanations are a last resort, for situations in which there do not seem to be any connections to other factors or behavior.

  o *What to do* –
    contact a psychiatrist (or other appropriate medical professional) for an examination.

● *Subtypes or Related Disorders*

➲ Autism and Asperger's Disorder

The most common subtypes of ASD/PDD are Autism and Asperger's Disorder. The two are very similar and there is some debate over whether Asperger's Disorder is really a separate disability or simply "High Functioning Autism" (HFA) (note: *HFA is not a formally defined diagnosis. It is an informal term used by some researchers for individuals with ASD and no mental retardation).* According to the DSM, people experiencing Asperger's Disorder do not have a clinically significant impairment in speaking skills, although they may experience difficulty understanding subtle aspects of speech such as irony, humor, and abstract concepts. On the other hand, the DSM says people experiencing autism may or may not have impaired speaking skills. Also, people experiencing Asperger's Disorder do not have clinically significant mental retardation (many have high IQs), while people experiencing autism may or may not experience mental retardation. Individuals with Asperger's Disorder may have more coordination problems than individuals with autism.

The defining characteristics of Asperger's Disorder, according to the DSM, are a significant impairment in social skills, and a set of limited and repetitive interests, behavior, or activities. The defining difference from autism is a lack of a developmental delay before the age of 3 in cognitive development, language, or behavior. Delay of some kind before the age of 3 is required for the autism diagnosis. Recent research shows no qualitative differences between people with Asperger's Disorder and those with autism who have relatively typical cognitive abilities (*Howlin, 2003*).

➲ Other PDDs

There are two other disorders which the DSM IV groups with Autism and Asperger's Disorder: Rett's Disorder and Childhood Disintegrative Disorder. **Rett's Disorder** only occurs in girls and is very similar to autism except that it is usually associated with mental retardation and involves loss of intentional use of the hands combined with a characteristic hand-wringing behavior. Some individuals with Rett's Disorder experience a significant loss of motor control.

The symptoms of **Childhood Disintegrative Disorder** (CDD) are nearly the same as those of autism. The primary difference is that the person shows normal development well past age 2 and then shows a sudden and significant regression/loss of skills. Following this, the symptoms and course are basically the same as autism, with the addition that significant mental retardation is more likely with CDD than with autism.

➲ PDD Not Otherwise Specified (PDD-NOS)

PDD-NOS is a catchall term for any condition that meets most but not all of the criteria for other PDDs, so it seems like it should be a minor part of the PDD/ASD population. However, statistically it is the most common diagnosis and accounts for more than half of all people with a PDD diagnosis (*Fombonne, 2005*). It is diagnostically defined by

significant deficits with social interaction along with either communication deficits or stereotypical behavior/fixations.

PDD-NOS includes **Atypical Autism**, which is defined as autism that does not meet the criteria because of late onset, odd symptoms, or some core symptoms too mild to count as significant.

➲ Autism and Deafness

There is a growing recognition of a population of individuals with both autism/ASDs and deafness. Although this is not a distinct diagnosis, people with this dual diagnosis present challenges to educational and support services. In addition, some intriguing initial studies of this population suggest that fluency in sign language may significantly improve social communication skills and the ability to form friendships, while decreasing some of the stereotypical behaviors *(Szymanski & Brice, 2008).* It is important to note that these benefits, if accurate, apply only to fluency in sign language, not to the use of isolated ASL signs as a communication supplement.

➲ Social Communication Disorders

Some researchers use the terms **Social Communication Disorders** to cover PDD/ASD and any other conditions which impact a person's ability to give and receive social signals. This could include many individuals with developmental disabilities or mental retardation who are not technically part of the ASD spectrum. Social Communication Disorders is a functional category rather than a medical diagnosis.

Causes

No one knows exactly what causes ASD. It is clearly rooted in something that affects the development of the brain early in development. Researchers can identify inheritance as the single most important factor, but there appear to be many genes involved, interacting in complicated ways. Other possible contributing factors include prenatal problems, environmental factors, and infections, among other things. At one time, researchers thought a person with ASD experienced "normal" cognitive development up to approximately age two, but they now believe the differences are present at birth.

Researchers have found that people with autism (in particular) have physical differences in several parts of the brain that involve social and emotional behavior, including the limbic system and the amygdala, and in parts of the cerebellum. In parts of the limbic system, in particular, there are more cells than usual and the cells are smaller than usual. Researchers find that the nerve cells involved with receiving basic sensory information (hearing, vision, touch, etc.) are fine, but there are changes in the parts of the brain that help integrate these centers and interpret meanings *(Minshew, et. al., 2005).*

For some reason, the brains of people with ASD also tend to be slightly larger and heavier than typical. The extra growth happens in several parts of the brain, including the white matter of the brain, which helps carry information from one part of the brain to

another. In children, this brain growth often leads to a slightly enlarged head. Usually the enlargement is not enough to be outside the "normal" range, but it is in the upper part of the "normal" range and leads to a slight but noticeable "big headed" appearance. However, by adulthood, the difference has usually faded and the individuals' heads appear "normal". These children's heads are not shrinking – their heads stop growing excessively and the "normal" population catches up *(Minshew, et. al., 2005).*

 No one knows exactly what this or the limbic cell changes mean. One theory proposes that parts of the brain may grow too fast or in a disorganized way, causing too many signals to be sent to other parts of the brain and "burning out" some of the brain's interconnections. Another theory suggests those interconnections simply do not develop "normally" to begin with. Unfortunately, much of the research is contradictory and derived from small sample sizes. In addition, if these neurological differences do turn out to be consistent, researchers still do not know if the differences are causes or consequences of autism *(Howlin, 2003).*

● *Alternative Theories About Causes*

There is a set of alternative theories about ASD which are NOT part of accepted medical research but are worth mentioning for their importance to ASD culture. These usually focus on an allergy or immune system cause for the disorders. This focus is based on the significant number of people with ASD who report digestive or allergy problems. There are many variations on this explanation, but the most popular include a dietary allergy to casine (egg proteins) or gluten (wheat protein), a damaged immune system due to childhood vaccinations, or differences in the digestive system that allow specific nutrients to enter the bloodstream in high concentrations and disrupt the brain. There is quite a bit of evidence against the vaccination damage theory, but some people still promote it. There is not a lot of evidence for or against the other theories, but most researchers are skeptical.

For supporters of these models, the explanations lead to many alternative therapies and diets. There are many anecdotal stories that these treatments have helped some individuals, and they cannot be ruled out. Some researchers suspect that dietary therapies may reduce some underlying digestive problems or allergic reactions which are distracting the person with ASD and contributing to their challenges. If that is the case, removing the digestive problems would not "cure" ASD but might improve attention and interaction, and decrease irritability. Physicians caution that such diets will probably not cause any harm but anyone using them should pay extra attention to maintaining good nutrition.

ASD Culture

Although it is not yet as robust as deaf culture, there is an emerging ASD culture, many members of which are persons with "High Functioning Autism" and Asperger's Disorder. Because of this, it is sometimes referred to as "Aspie Culture." The internet has supported the development of this culture by allowing individuals with ASD to locate and interact with each other efficiently. In addition, the absence of social cues in e-mail, internet chat, and other online text functions, which many people without disabilities find limiting, is a great advantage for people with ASD. In these formats, challenges with social communication decrease and focusing directly on the literal content of the message is appropriate.

Some people in the ASD culture take the perspective that ASD is not a disorder to be cured, but simply a difference, similar to cultural differences, which should be celebrated and accommodated. This perspective is a central belief of the Autistic Rights Movement, which advocates for more tolerance of the behaviors and preferences of people with ASD. In some ways, this perspective is similar to that of the National Federation of the Blind, which proposes that the barriers faced by people with blindness are all culturally imposed and blindness is, at most, an inconvenience, not a disabling condition. The Autistic Rights Movement proposes that persons "on the spectrum" (with ASDs) are just a variation within the range of normal human cognitive functioning. They refer to the general population as "**neurotypicals**" and promote tolerance of "**neurodiversity**". They strongly object to any efforts to "cure" individuals with autism/ASDs and they promote the use of accommodation and training in adaptive skills.

In contrast, a number of parent and advocacy groups in the ASD community strongly support treatment programs (such as Applied Behavioral Analysis, see below) to help children with ASD improve their communication and social skills. They criticize the Autistic Rights Movement as being focused only on high functioning individuals, with no consideration for others with more significant challenges or the importance of helping people function in their local communities. The Autistic Rights Movement feels these groups are trying to "cure" ASD. There is often a great deal of emotional tension between these two aspects of ASD culture.

An interesting outcome of the Autistic Rights Movement is Autreat – an annual, national conference designed to match the preferences of persons with ASD. It is usually held on a small town college campus in a relatively rural setting, so there is less traffic, noise, and lights to distract individuals. Conference rooms are large, with couches instead of chairs, indirect lighting and natural sunlight, and a relatively relaxed format, allowing people to come and go as they wish, sit alone or in groups, or engage in any stereotypies they choose. Individuals wear color-coded badges to indicate if they A) are open to talking to new people, B) would rather be left alone, or C) are mildly interested in new people. At one Autreat conference there was a panel/forum entitled "Ask a Neurotypical", as a counterpart to panels of persons with ASD often held at "mainstream" conferences on ASD.

Possible Coexisting Conditions

Individuals with ASD are also at increased risk for:

➤ Seizure disorder (some researchers think seizure disorder is quite prevalent among persons with ASD but is frequently masked by the ASD features)

➤ Depression (as with seizure disorder, some researchers think depression is quite prevalent but masked)

➤ Hearing Loss or Deafness

➤ Tuberous sclerosis complex (TSC) - a genetic disorder that causes tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs

➤ Food allergies

➤ Gastrointestinal problems

➤ Obsessive-compulsive disorder

➤ Attention Deficit Hyperactivity Disorder (ADHD) – (the DSM-IV does not allow diagnosis of both ADHD and autism in one individual, but as of 2008 the DSM-V working group was recommending that be changed)

➤ Anxiety Disorders

Incidence Statistics

The statistics below are from a range of studies, some with large samples, some with smaller samples; some older, some more recent. We are providing the statistics to indicate general trends, but they should not be taken as absolutely final and should not be used to inform vocational rehabilitation services. The employment services and supports for any person with ASD should be rooted in the features of that person, not in statistical information. Also note that, in the research literature, the terms Autism and ASD are sometimes used interchangeably and sometimes distinguished. The use of these terms below reflects that of the original source of each statistic.

➢ 1 in 150 children (0.67%) have ASD (this rate is based on prevalence in 8-year-olds in 2002 averaged across 6 states in the U.S.) *(CDC, 2007)*

➢ There was a 20% increase in the rate of autism each year from 1992 – 2003, with a cumulative increase of 805% *(Hollenbeck, 2004)*

➢ The ratio of males to females with autism is 4:1, but this varies with cognitive functioning. Among people with "high functioning autism" or Asperger's Disorder, the rate is 10:1, while among those with significant mental retardation, the rate may be as low as 2:1 *(Howlin, 2003)*

➢ 1 in 76 (1.3%) of children with deafness have ASD, approximately twice that among the general population of children *(Szymanski & Brice, 2008)*

➢ 3.5 % of children with autism have pronounced or profound hearing loss/deafness. Among children in the general population, the rate is approximately 0.2 %. *(Rosenhall et al., 1999)*

➢ 94% of a sample of children with autism experienced sensory abnormalities, compared to 65% of children matched for age and IQ. A larger study confirmed the 90%+ figure but had no matching group *(Leekam et al, 2006)*

➢ People with autism who had one sensory abnormality are more likely to have other abnormalities across multiple sensory domains *(Leekam et al, 2006)*

➢ Frequency and type of sensory abnormalities in children with autism do not vary with IQ. In children with developmental disabilities, frequency and type DO vary with IQ. *(Leekam et al, 2006)*

➢ 18% of children with autism and normal hearing have hyperacusis – they experience normal-volume sounds as painfully loud *(Rosenhall, et al., 1999)*. Among the general population, the rate is approximately 8% *(Baguley, 2003)*

➢ 70% of children with ASD experience gastrointestinal problems (abnormal stools, frequent constipation, frequent abdominal pain, frequent vomiting) compared to 42% of children with other developmental disabilities and 28% of children with no diagnosis *(Myers & Johnson, 2007)*

➢ 25% of people with autism experience seizure disorders *(Howlin, 2003)*. Some researchers suspect the rate is higher but the seizure symptoms are masked by

autism symptoms *(Minshew, et. al., 2005).* Some studies report rates as high as 38% *(Tuchman & Rapin, 2002)*

➢ Approximately 50% of adults with autism have an IQ below 50. 20% have an IQ in the normal range. Verbal skills are usually more affected by this than non-verbal skills *(Howlin, 2003)*

➢ Up to 75% of adults with ASD are treated with psychotropic medications (ones that affect the mind, emotions, or behavior). 45% of children and adolescents with ASD are treated with psychotropic medications *(Myers & Johnson, 2007).*

➢ Up to 75% of people with strong verbal skills and autism exhibit echolalia of some form during their life *(Prizant, 1983).* Most exhibit it in early childhood and later outgrow it or control it.

➢ 60% of a sample of 61 children with ASD displayed occasional aggressive behavior to others or property. 43% had sudden changes of behavior for no apparent reason, and 51% displayed self-injurious behavior *(Amet, 2009).*

➢ 81% of children in that sample who experienced self-injurious behavior have sleep disturbances and 80% have abnormal bowel movements *(Amet, 2009).*

➢ 73% of a sample of 100 children with ASD had problems sleeping, compared to 52% of a sample of children with no diagnosis *(Polimeni et al., 2005)*

➢ 15% to 37% of people with autism have a diagnosis for a second medical disorder as well *(Jensen & Sinclair, 2002).*

➢ Up to 4% of people with autism have Tuberous Sclerosis – a genetic disorder that causes defuse tumors in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs *(Zafeiriou, 2007).* This rate means people with autism are 100 times more likely than others to have Tuberous sclerosis *(Fombonne, 2005).* For people with both autism and seizure disorders, the rate is between 4% and 8%. Among people with TS, the rate of autism may be as high as 65%.

➢ Up to 6.5% of people with autism have Tourettes Syndrome *(Zafeiriou, 2007).*

➢ 10% of people with autism show some degree of "savant" abilities, ranging from "splinter skills" such as the memorization of trivia to remarkable and rare genius-like talents in musical performance, art, or other activities *(Treffert, 2006).*

➢ Only 50% of people with "savant" abilities have autism *(Treffert, 2006).*

➢ Between 0.6 and 1.4 % of people with significant mental retardation have "savant" abilities. Because the population of people with mental retardation is so much larger than the population of people with autism, this small percent represents nearly 50% of people with savant abilities *(Treffert, 2006).*

Common Treatments, Medications, and Side Effects

There is no accepted, standard medical treatment for ASD. The most commonly accepted treatment is educational intervention. There is one drug approved for children with ASD, but its use is very limited (see below). No treatment can "cure" ASD, but these treatments can lead to significant improvements in the symptoms a person experiences.

● *Educational Interventions*

As with most of the research in ASD, educational interventions are almost entirely focused on children. There is great diversity in the types of intervention, but the most successful and widely accepted technique is Applied Behavioral Analysis (ABA).

It is worth noting that, technically, ABA is a technique for reducing or stopping a specific behavior. There is no interpretation of the reason for a behavior and no goal beyond stopping the behavior. In the ASD community, the term has been modified to mean a systematic use of ABA strategies to improve socialization, communication, and overall functioning by targeting specific sequences of skills, mimicking those of typical child development. This goes well beyond the basic ABA approach and requires a theoretical model of child development and how children with ASD differ from typical development. There are many different such theories, each giving rise to a different ABA-based techniques, and each with its own name (*Jensen & Sinclair, 2002*).

In practice, these ABA-based techniques (and others like them) are seldom used by themselves. Instead, the most successful intervention programs combine the different techniques and theories to deal with the great diversity of children with ASD. There are many of these blended intervention programs in the ASD community. Because these programs are so focused on early childhood skills and development, most are not useful for vocational rehabilitation issues.

However, for any particular client with an ASD, it can be useful to ask about the kinds of techniques which have been useful for him or her.

A few techniques and programs are proving useful in employment situations and are worth discussing here.

➲ TEACCH

TEACCH (Training and Education of Autistic and Related Communication Handicapped Children) is one of the most widely used educational intervention programs for children with ASD. It is a statewide program in North Carolina which is based at the University of North Carolina at Chapel Hill. It is of interest here because its approach to training, in some ways, matches the philosophy of vocational rehabilitation (TEACCH has been

providing supported employment services on a modest scale since 1989, but its primary focus is childhood educational intervention).

TEACCH focuses on maximizing the skills of children with ASD by focusing on their relative strengths, rather than trying to "fix" their symptoms. To accomplish this, TEACCH alters the physical and organizational structure of the classroom to support the common needs of children with ASD and minimize the impact of the disorder. TEACCH staff members then apply ABA-based intervention techniques in this environment to improve social skills, communication skills, etc. This system of environmental supports is relatively unique among ASD educational intervention programs. This aspect has also attracted some criticism for lack of generalizability *(Northeast Tennessee Autism Society, 2002; Myers & Johnson, 2007)*. But in many ways it resembles the vocational rehabilitation strategies of accommodations and assistive technologies.

Because of these similarities, it is worth reviewing some of the supports which TEACCH recommends:

- ➢ **Structure:** The environment should be highly structured, with specific activities occurring only in specific places.
- ➢ **Marking:** the work spaces should be clearly marked physically, including colorful marking on the floor, specific arrangement of furniture, and other concrete and visual clues.
- ➢ **Visual Communication:** Staff should use picture-based schedules and work systems to outline the activities for the children.
- ➢ **Routine:** There should be a clear and regular sequence of activities. The routine should be listed on the schedules.
- ➢ **Sensory distractions** should be minimized to improve concentration.
- ➢ **Individualized:** Specific activities and supports should be based on a child's interests, skills, and needs

➲ Picture Exchange Communication System (PECS)

PECS is a system of graphic cue cards used for communication. It specifically focuses on helping children with communication challenges learn to initiate communication with adults and other children. It was originally developed for children with ASD but educators now use it for children with a variety of disabilities. A teacher gives a child a set of cards with a different symbol on each. The child can then give those cards to the teacher or other adult to ask for the item symbolized or, in combination with other card symbols, comment upon the item or activity. This allows children to communicate and interact without needing strong language skills. The name PECS is trademarked by Pyramid Educational Products, which offers a set of specialized resources, guides, and related products. However, within the ASD community the term has become somewhat generic and there are other sources for additional images, cards, and resources. It should be noted that the full PECS system includes a graduated system of syntaxes of increasing difficulty through with children move as their communication skills increase. The syntax

systems are rooted in a model of children's language acquisition and the ultimate goal is to teach a full range of communication, not just how to initiate requests.

In employment settings PECS-type communication systems are proving to be a useful supplement even for people with adequate verbal skills. For example, the widely known Walgreens project features a PECS-based communications system *(Emmett, 2009)*.

➲ Social Stories

Social stories are narrative descriptions of social situations that help children with ASD understand particular situations or activities which might be confusing to them. They are told from the perspective of a child (first person) and discuss what things happen in that situation, what people are there, what those people do or say, etc. The goal of social stories is to improve a child's understanding of a situation and help the child learn what sorts of behavior are appropriate. They are not prescriptive stories defining what the child should do, but descriptive stories helping the child understand what is going on. Michigan educator Carol Gray developed the Social Stories technique in 1991. She has created a set of criteria to guide writers of social stories and continues to sell instruction manuals and host workshops.

Some vocational rehabilitation practitioners have found social stories to be a useful technique. They can be used to help clients understand the initial VR interview, the VR process, the vocational evaluation process, etc. In the workplace, they can be used by job coaches to help clients understand the social aspects of work and the work day *(Emmett, 2009)*.

Social stories work best to explain broadly defined situations, such as "What to do in the Lunch Room" or "What to do When You Arrive at Work". They provide "directive" information on what types of things to do and why.

There are several elements to keep in mind about social stories:

➢ Ideally the stories should be written by someone familiar with Gray's criteria, either by reading one of her manuals or attending a workshop. Among other things, Gray has identified 5 specific types of statements to include in each story and the relative proportions of each.

➢ Ideally the person writing the story should meet the client, the client's family, and the VR counselor or job coach to discuss potential issues or situations to address through social stories

➢ Ideally, the story should be provided to the client well before he or she next encounters the situation or issue.

However, even an imperfect social story written as a best effort attempt can be helpful, as long as it focuses on explaining a situation and avoids dictating "good" behavior.

➲ Comic Strip Conversations

Comic strip conversations replace the narrative of social stories with a sequence of drawings, including stick figures, speech bubbles, and thought bubbles, to describe a target social situation. Like social stories, comic strip conversations were developed by

Carol Gray as a tool to improve a child's understanding of a social situation so the child can figure out what sort of behavior is appropriate.

In contrast to social stories (which explain the purpose and associated features of broad situations), comic strip conversations help a person with ASD figure out what to say or do in a specific situation. Instead of "What to do in the Lunch Room", a comic strip conversation might be about "How to Start a Conversation in the Lunch Room", or "How to Ask for Help on a Job Task" *(Emmett, 2009)*. The comic strips let people who are strong visual learners explore different ways of responding.

In addition, because a comic strip conversation includes both thought bubbles and speech balloons, it helps people with ASD understand that the thoughts of others might be different from what they say. This is important information for people who tend to focus on concrete details.

Comic strip conversations can also give a person a chance to express thoughts, feelings, or concerns which are difficult for them to describe. One professional reports dramatic success using comic strip conversations as an intervention with children with ASD who are having a temper tantrum and either cannot explain what is upsetting them or cannot understand the attempts of others to explain things *(Sparapani & Boll, 2006)*.

As with social stories, some vocational rehabilitation practitioners have found comic book conversations to be a useful tool for supporting a person with ASD about specific work situations *(James Emmett, 2009)*.

There are several elements to keep in mind about comic strip conversations:

➢ Ideally the comic strip conversations should be drawn as a joint activity between the client and the counselor or job coach. This makes the comic strip a two-way exchange and allows the person with ASD freedom to explore options. It also better anchors the lesson in the client's mind.

➢ Comic strip conversations can be done as a group activity if several people with ASD are together and wrestling with similar target situations. Professionals working with children with ASD report that the children find it interesting and fun *(Sparapani & Boll, 2006)*.

➢ Once the comic strip conversation is complete, it can be used as a visual prompt for the person, either in a personal area (such as a locker) or in the work space.

➢ If the individual does not have strong reading skills, the thought bubbles and speech balloons can be filled in with drawings and symbols.

➢ Once the person is familiar with comic strip conversations, colors can be added to express emotions of the figures in the cartoons.

➢ As with social stories, there is a book from Carol Gray on comic strip conversations (although it is much shorter that those on social stories).

➢ If the technique is useful for a person, it can be taught to co-workers and supervisors.

➲ Scripts

Scripts combine the specificity of comic strip conversations with the text format of social stories. The technique involves writing a play-like script of a target situation, including notes on actions and, possibly, emotions. Although this technique will work best for someone with some reading skills, it could be useful for a person who does not read if the script is read aloud.

Scripting was developed as a behavioral intervention for children with ASD by Patricia Krantz and Lynne McClannahan of the Princeton Child Development Institute in 1993 *(Krantz, 2000)*. The initial focus was on developing, in children, the "mechanical" skills of participating in the give and take of a typical conversation. McClannahan later discussed some cognitive benefits of the technique in helping children understand the social situations in which the conversations take place. Vocational rehabilitation professional James Emmet has extended the technique as a cognitive tool to help adults with ASD understand and prepare for social situations *(Emmet, 2009)*.

As with comic book conversations, scripts work best for addressing specific social situations and for helping a person understand what to say or how to act.

Also like comic book conversations, it is best to involve the person with ASD in writing the script so it becomes a constructive activity for them. If the client does not have strong writing/reading skills, the support person can be responsible for writing down the script as the two of them create it. This activity, too, can be done as a group activity.

Once the script is finished, the person with ASD and whoever else helped create it should act it out. It is best to have the person with ASD portray their own role in the script and not try to have them switch roles.

● *Drug Treatments*

In 2006 the FDA approved the antipsychotic drug **Resperidone** for use in controlling challenging behaviors in children with autism, but it is reserved for situations involving children with "severe and enduring problems of tantrums, aggression, and self-injury." The original researchers specifically warn doctors not to use it with children who are experiencing mild aggression or recent "explosive" challenging behavior *(Scahill, 2008)*. In addition, the researchers recommend it as a supplement to behavioral therapy, not as a replacement for it. Resperidone does not address any other associated features of ASD.

Resperidone is classified as an atypical antipsychotic, and works by blocking some of the dopamine receptors in the brain to reduce dopamine activity. It is used to treat schizophrenia in young adults, bipolar disorder in children and young adults, obsessive-compulsive disorder, and Tourette syndrome, in addition to its use in children with autism.

It can be taken as pill, a liquid, or as a shot given once every two weeks.

Possible side effects of Resperidone include anxiety, uncontrolled movements, constipation, nausea, upset stomach, runny nose, rash, vision changes, abdominal pain, inability to control urination, and weight gain (FDA, 2006)

A few other drugs have been used to treat specific symptoms of people with ASD, but there is no standard drug treatment for ASD.

Possible Functional Issues

Because of the large range of possible characteristics of people with ASD, the list of possible functional issues is quite large. **No person will experience all the issues listed below**, but it is worth reviewing the list for any particular client with an ASD. The list below is focused on functional issues that could impact workplace performance. It does not address medical or independent living issues.

After reviewing the list of functional issues below, readers should review the Possible Job Accommodations section, later in this report, for ways to address the functional issues a particular person experiences.

➢ Dependence on routine

➢ Expectation that initial events or activities in a new environment are a new routine

➢ Anxiety over changes in routine or lack of routine as framework in new environment

➢ Dependence on environmental prompts to anchor routines and activities

➢ Difficulty following complex instructions or requests

➢ Difficulty following written instructions or requests

➢ Difficulty understanding the sequence of steps in a long series

➢ Difficulty summarizing information or messages

➢ Difficulty planning or organizing

➢ Difficulty selecting a sequence in which to carry out steps

➢ Strong ability to focus intently on tasks at hand

➢ Ability to understand visual or iconic instructions

➢ Strong ability to notice details

➢ Anxiety about waiting, changes in schedule, or new routine

➢ Anxiety about new locations or people

➢ Attraction to orderly systems or machines

➢ Strong ability to sort and categorize

➢ Strong ability to perform detailed tasks

➢ Tendency to fixate on one or two topics

➢ Tendency to express frustration, anxiety, or uncertainty by talking about topics on which they fixate

➢ Strong ability to interpret activities and environment using one or more personal themes

➢ Difficulty understanding that others do not share their specific interests or world view

- ➢ Difficulty interpreting organizing themes of others for activities and work environment

- ➢ Limited or no verbal skills

- ➢ Strong verbal skills, but specialized vocabulary focused on favorite themes

- ➢ Strong verbal skills which mask difficulties with social signals

- ➢ Difficulty understanding the give and take of conversational flow

- ➢ Difficulty understanding "shades of gray" in rules and guidelines

- ➢ Blunt honesty in talking with others

- ➢ Tendency to become angry toward or distrustful of people who seem to violate the person's literal interpretation of rules and guidelines

- ➢ Literal interpretation of metaphors and expressions in everyday language

- ➢ Need for silent, processing time during long conversations to improve comprehension

- ➢ Tendency to be shy or minimally interactive with others, preference for working on solitary tasks.

- ➢ Tendency to be too outgoing toward others, not recognizing when to withdraw

- ➢ Difficulty reading social cues, both verbal (suggestions) and non-verbal (body language, tone of voice)

- ➢ Difficulty understanding sarcasm and some types of humor

- ➢ Tendency to express emotions behaviorally, sometimes in challenging ways

- ➢ Tendency to repeat a statement multiple times rather than rephrasing when others have not understood the first statement (difficulty understanding another's confusion or point of view)

- ➢ Discomfort or distraction due to lights, sounds, odors, textures, etc. that do not bother others

- ➢ Strong attraction to specific lights, sounds, odors, textures, etc.

- ➢ Low tolerance for and difficulty concentrating in messy, chaotic environments

- ➢ Low tolerance for and difficulty concentrating in brightly lit environments

- ➢ Low tolerance for and difficulty concentrating in noisy environments

- ➢ Reduced response to notification signals, such as telephone rings, flashing lights, honking horns, fire alarm, calling of name

- ➢ Difficulty processing more than one mode of sensory information at a time – verbal and visual, for example. Preference for one mode at a time.

- ➢ Tendency to rock back and forth, make repetitive noises, or perform other repetitive actions when anxious, bored, confused, etc.

- ➢ Clumsy gate

- ➢ Limited walking ability

- Difficulty navigating between closely placed furniture or objects
- Tendency to knock things over
- Difficulty with fine motor activities – buttoning buttons, grasping small objects, drinking from glass
- Difficulty with mechanics of speech
- Difficulty with hand-eye coordination
- Difficulty writing
- Strong memory skills on specific topics
- Strong visual skills

Initial Interview Considerations

● *Interview Accommodations*

➢ Find out well in advance:

- How the person prefers to communicate – verbally, writing, sign language, picture exchange system, communication device, etc.
- If the person has any sensitivities – bright lights, noise, activity, textures, odors, etc.
- If the person can read

➢ Hold the interview someplace which:

- Has indirect, soft lighting
- Has few distracting background sounds (a "white noise" machine might help)
- Has few distracting background activities – people moving around, etc.
- Has no clutter
- Has plenty of room to walk between objects (furniture, etc.)
- Has comfortable furniture

➢ Well in advance, provide the person with:

- An outline/schedule of the interview, with a unique symbol associated with each activity or phase
- A social story of the interview, if possible (see Social Stories, above)
- A social story of the vocational evaluation process, if possible
- A social story of the vocational rehabilitation process, if possible

➢ During the Interview, provide the person with:

- Another copy of the outline/schedule, in case they forgot the one you sent
- Cards or small sheets of paper, each with a copy of the symbols from the outline/schedule, to represent where you are in the schedule. As you move through the schedule from item to item, bring out the card or paper with the symbol for that item.
- Plenty of long pauses to think and process. Let them set the pace.
- Plenty of time to respond to any questions.

➢ Speak literally, avoid any expressions or sayings.

➢ Speak in direct, clear language using a calm tone of voice.

➢ Provide a sign language interpreter if needed.

➢ Do not be bothered if the person does not make eye contact, exhibits repetitive behavior, or repeats phrases back to you. (However, repetition of your phrases may be the person's way of saying they do not understand your question or do not know how to answer. Alternatively, it might be their way of saying they do understand what you said and are processing it.)

➢ Be careful to live up to any commitments you make, such as mailing material to them or finding out about something before the next meeting. It is easy for people with ASD to take a casual offer or agreement as a firm promise and later feel betrayed if the other person does not live up to it. Similarly, be careful about skipping over any "minor" agency policies or steps in a process. The person may believe that "rules are rules."

➢ Do not try to make any jokes or funny comments until you understand the person's sense of humor and how literally they take things.

● *Initial Questions*

Although it is important to ask a client about their experience with the possible characteristics in the Spectrum, it is also important to understand each client as a person. So the list below has a few 'Get To Know Me' questions scattered throughout to keep the interview from becoming too dry and mechanical. The list also does not include basic questions that would be on standard intake forms.

Because of the wide range of possible features of ASD, the list of questions below is very long. It would not be productive to ask them all. Review the list and highlight the ones that seem most relevant to you. Be sure to keep a few "Get To Know Me" questions in your list.

➲ Suggestions About Asking Questions

- Keep questions limited so you do not overwhelm the client.

- Do not read the questions straight from this list. Rephrase them in your own way.

- Watch for signs the person might need a break. They may not be used to answering so many questions at one time.

- Expect that the person may not answer a question directly or may go off topic. Let them say what they want to; think about whether what information their answer gives you; then, if necessary, try asking the question again or in a different way.

- The person may not be able to describe cause and effect very well, or they may not see the same cause and effect relationships you do. Again, think about what their answer tells you about them, in addition to whether it was the kind of answer you expected.

- The person may not know how to ask for help on a question. Watch for signs of frustration or confusion. Try rephrasing the question. Try asking them what is "wrong" or "hard" about the question.

- If you are not able to help them understand a question, skip that question and move on.

➲ Possible Initial Interview Questions

- ➢ How does the person prefer to communicate? Verbally, sign language, picture exchange system, communication device, etc.?

- ➢ What sensitivities, if any, does the person have? Do lights bother him or her? Sounds? Textures?

- ➢ What specialized behaviors, if any, does the person use to express themselves? Do they flap their arms, rock back and forth, sing, etc.? What do those behaviors mean for the person?

- ➢ What specific types of places or activities that upset the person?

- ➢ What kinds of places are most soothing or pleasant for the person?

- ➢ What kinds of activities are most soothing or pleasant for the person?

- ➢ What does the person do on a typical weekend?

- ➢ What activities does the person do with friends or family?

- ➢ What topics, if any, does the person like to talk about or study?

- ➢ What medical conditions, if any, does the person have?

- ➢ If there are medical conditions, what family history is there of those conditions?

- ➢ What medications is the person taking, if any?

- ➢ What side effects does the person experience from the medications, if any?

- ➢ How often, if ever, does the person have trouble sleeping?

- ➢ How often, if ever, is the person sleepy during the day?

- ➢ How often, if ever, does the person have abdominal pain, cramps, diarrhea, etc.?

- ➢ How often, if ever, does the person experience seizures?

- ➢ What was school like for the person?

- ➢ What subjects in school did the person like best? Why?

- ➢ What subjects in school did the person like the least? Why?

- ➢ What part of the school day did the person like best? Why?

- ➢ What learning techniques work best for the person?

- ➢ What educational intervention programs, if any, did school staff use to support the person's learning and behavior? What aspects of those intervention programs worked the best?

➢ What behavioral interventions, if any, have worked best for the person?

➢ How often, if ever, has the person caused harm to themselves – hitting themselves, pulling hair, etc.? What triggered the behavior?

➢ How often, if ever, has the person hurt someone else in anger or frustration? What triggered the behavior?

➢ How often, if ever, has the person damaged property in anger or frustration? What triggered the behavior?

➢ What is the best response, if any, to the person's challenging behaviors, if any?

➢ What does the person enjoy reading?

➢ What hobbies or skills does the person have?

➢ Who is the person's best friend? Where did they meet? What do they do together?

➢ How often, if ever, does the person bump in to furniture, chairs, etc.?

➢ How difficult is it for the person to eat or drink?

➢ What is the person's favorite food?

➢ How important is a neat and orderly environment to the person?

➢ How often, if ever, does the person get upset about changes in routines?

➢ How often, if ever, does the person get upset about having to wait for an appointment or event?

➢ What does the person do when he or she gets upset or confused? How do they express those emotions?

➢ How does the person prefer to organize their time?

➢ What does the person use to remind themselves about things? A notebook? Pictures on cards?

➢ What is the persons' favorite animal?

➢ What things or activities make the person confused?

➢ What sign language, if any, does the person use?

➢ How often, if ever, does the person seem to withdraw from what is going on around them?

➢ What is the funniest story the person knows?

➢ What is the funniest story the person knows about themselves? *(possible insight on the kinds of social challenges they experience)*

➢ How often, if ever, does the person get confused about what others are trying to say?

➢ What social situation does the person like the least?

➢ What social situation does the person like the most?

➢ Which does the person like better: working by themselves on a job, working with one or two other people, or working with a large group?

- How often, if ever, does the person not seem to see or hear things that other people notice? What sorts of things do they not see or hear?

- How long can the person stand or walk comfortably?

- How often, if ever, does the person do something over and over and over? What triggers that behavior? What does the behavior mean to the person?

- What was the person's favorite trip – vacation, school, etc.?

- What is a typical morning like for the person?

● *Initial Observations*

- How are their fine motor skills? Are they able to pick up small objects, such as a pencil?

- How are their gross motor skills? Did they bump into things or have trouble moving around furniture?

- How well can they walk? Was there any awkwardness in their gait?

- How is the persons' hand-eye coordination? Do they knock things over or drop things?

- How well can they speak? Are their words clear and easy to understand?

- How are their language skills? Do they use some words in an odd way? Do they fixate on a particular topic or particular details?

- How well can they write?

- How well can they read?

- How well do they seem to understand what you say?

- How are their social skills? Do they seem friendly, aloof, awkward?

- Do they take long pauses to think during a conversation?

- If the person became anxious or confused during the interview, how did they act?

- Does the person have any obvious repetitive motions, actions, or phrases that might be distracting to others?

- Does the person seem to fixate on details and have trouble with overall goals or concepts?

- Does the person seem to retreat to talking about favorite topics or fixations when they feel anxious or confused?

Career Planning

● *Vocational Evaluation Challenges*

Traditional, formal vocational evaluations are so problematic for people with ASD that some professionals advise against them entirely.

People with ASD often value routine, have difficulty with verbal instructions, get easily over stimulated, and become confused in new social settings. A typical vocational evaluation will involve putting the person in a strange facility, possibly in a room full of people or noises, giving them a series of evaluations (each with different instructions), and then asking them to come back the next day for more testing.

One state VR agency discovered that, of their eligible clients with ASD whom counselors sent for vocational evaluation, more than 90% withdrew from VR services before finishing the evaluation. Those few who did complete the vocational evaluation had a high job placement rate, probably because they were higher functioning. Those with more challenging features had been filtered out.

The ideal vocational evaluation for a person with ASD is a thorough interview (ideally as a series of short interviews held in a place that is familiar and comfortable for the person) **followed by observations of the person in their normal activities and locations and by observations in one or two novel situations**. It should also include interviews with family members, teachers, and support providers. An experienced vocational evaluator can use this information to make a summary report and recommendations.

Be sure that the person with ASD gets a clear orientation about what to expect during the vocational evaluation and what is expected of them. This might include a social story and a schedule with icons.

➤ Factors for a Vocational Evaluation Report

Be sure that any vocational evaluation addresses at least the following factors:

- Learning style preferences (including insights from school/home training experiences)
- Sensory sensitivities
- Sensory attractions / preferences
- Topics of fixation
- Communication skills and support needs
- Communication preferences
- Social skills and support needs
- Physical skills, abilities, or challenges

- Cognitive skills, abilities, or challenges

- Sources of anxiety or concern to the person

- Triggers for challenging behaviors (and effective responses)

- Hand-eye coordination

- Assistive technology needs

- Transportation needs

- Existing community supports

If a more formal vocational evaluation is necessary for procedural reasons, it is important to communicate with the evaluator well in advance and make sure the evaluation process is adapted to the characteristics of people with ASD. The following accommodations are helpful:

➢ **Vocational Evaluation Accommodations**

- Use a quiet, orderly, gently lit room.

- Use visually-based evaluations (see below), even if the person has some verbal skills.

- Use evaluations that can be given verbally and have no time limit (see below).

- Give the person plenty of time to process instructions or prepare for a transition to a new assessment.

- Provide a visually-based schedule of the day, using symbols/icons for different events and assessments, and update the person frequently on where in the schedule they are.

- Provide a social script (a story format description), if possible, describing what happens during a vocational evaluation. Give it to the person well ahead of time.

In 2002, a group of vocational evaluators and ASD specialists in Chicago reviewed vocational evaluation options and made the following suggestions for specific instruments and approaches (*Emmett, 2004, except where noted*).

➢ **Career Assessments** (if necessary)

- Job Shadowing / Work Samples

- *Reading Free Interest Inventory* - uses pictures of individuals in different occupations and does not require reading comprehension or written language skills.

- *Valpar Component Work Samples (VCWS)* – a set of short representative tasks from different occupations/activities. Individuals are taught each task, then asked to repeat it several times to record how quickly they learn (improve their time on) each task. Requires no writing, can be conducted in familiar location

by familiar people, and is criterion referenced. (VCWS was previously out of print, VCWS is now available again from Bases of Virginia, LLC.).

➢ **Achievement**

- Review of academic record and assessments

- *Peabody Individual Achievement Test-Revised (PIAT-R)* - an achievement test of receptive vocabulary for Standard English. It is delivered one-on-one, can be delivered orally, most responses can be done with pointing, short segments, no time limit.

- *Wide Range Achievement Test (WRAT)* - measures basic academic skills of word reading, sentence comprehension, spelling, and math computation. Can be delivered orally, segments are short, requires writing.

- *Peabody Picture Vocabulary Test* – tests receptive vocabulary, no expressive verbal skills are necessary, no time limit.

➢ **Independent Living Skills / Adaptive Behavior**

- Community-based observations

- *The Street Survival Skills Questionnaire* – measures independent living skills and vocational expectations. Given orally, responses may be given by pointing.

➢ **Social Skills**

- *Observation Profile for Children with Asperger's Syndrome* – a list of behaviors to observe key aspects of social interaction and social communication. From the book Asperger's Syndrome: A Practical Guide for Teachers (*Cumine, Leach, & Stevenson, 1998, David Fulton Publishing*).

- *Autism Social Skills Profile* – a list of skills and behaviors to measure social functioning. Designed for children and adolescents, it could be used for adults as well and is relevant for non-ASD social communication disorders. The developer has done extensive follow-up statistical analysis to confirm that the measure works. From the book Building Social Relationships: A Systematic Approach to Teaching Social Interaction Skills to Children and Adolescents with Autism Spectrum Disorders (*Bellini, 2006, Autism Asperger Publishing Company*) (suggested by *Baker, S., 2009*).

- *Assessment for Social Skills Training* – a list of 70 skills that are common social challenges. Designed for children but could be used for adults. It is focused primarily on ASD. From the book Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communications Problems (*Baker, J., 2003, Autism Asperger Publishing Company*) (Suggested by *Baker, S., 2009*)

➢ **Sensory Issues**

- *Pearson Adolescent/Adult Sensory Profile* – an adaptation of an established children's sensory profile, this is one of the few suitable for adults. It uses a 60-item survey about how often the person responds to different sensory experiences *(suggested by Ford, 2009).*

● *Career Planning Issues*

➲ Problems with Job Coaches

Job coaches who are unfamiliar with people with ASD can make work adjustment significantly worse for a client and lead to loss of the job (*James Emmett, 2009*). Although much of the research literature recommends job coaching for people with ASD, many common job coaching activities are inappropriate for clients with ASD and should be avoided.

➢ Do Not Become Embedded in the Person's Routine. As discussed above, people with ASD usually value routine and often will begin building a routine and set of expectations from the first day on the job. If the job coach is a prominent part of the person's work environment at the start, the person will come to expect that job coach to be there, prompting them, every day. Attempts to fade the prompts out a week or two later will be very difficult and may cause the person to become frustrated or simply "lock up." The person will stand there waiting for the job coach's prompt.

➢ Be Cautious with Verbal Prompts. Spoken reminders and prompts seem to be especially noteworthy and salient to people with ASD. For some reason, a person is more likely to embed verbal prompts in their routine than non-verbal prompts. If the job coach is frequently stepping in to say things like "Now, be sure you check…" or "The next step is…", it will be much harder to remove those prompts later on without upsetting the person.

➢ Use "point prompts." Point prompts consist of touching the person gently on the shoulder to get their attention and then, without speaking, pointing to indicate the next step. These prompts are much less prominent to the person with ASD, less likely to be embedded in routines, and easier to fade out.

➢ Use Modeling and Visual Prompts. Demonstrate how to do something, without speaking. These also are less prominent to the person and easier to fade.

➢ Use Environmental Prompts. These are diagrams, icons, visual markers (lines on the floor, colors on the floor, room partitions, etc.) which help the person orient themselves in the schedule and work space. They might include reference sheets in a notebook or labels placed on tools. These prompts can support the person's routine and be left in place after the job coach leaves.

➢ Support "Natural" Prompts and Resources. Find out which co-workers or on-site support/training staff the person could use on a regular basis for questions or reminders. The job coach should support them in creating a system of appropriate prompts which can remain in place after he or she leaves. By acting as a consultant, advisor, and monitor for these natural supports, the job coach can stand back from the actual work activities and not become embedded in the person's routine.

➲ Other Career Planning Issues

➢ Routines and predictable schedules may be very important to the person. However, endless repetition with no flexibility or variety may bore them. A good middle ground is a job with a relatively small set of job activities that can be scheduled beforehand so, even though each day may be slightly different, the person can know ahead of time what they will be doing. Part of the person's regular routine then becomes checking the schedule each day. This gives them better coping skills later on if the job tasks need to change in some way.

➢ If possible, try to match the individual's existing interests to the job. They may have a very deep but narrow knowledge base which can be an asset in the right situation. However, this often is not possible. Alternatively, you might try to frame job tasks in terms of the person's topic of interest, using the language and categories of that topic as a metaphor, but be careful that they do not take it too literally.

➢ Assess how the person learns best. Many people with ASD have strong visual skills and learn best with illustrations, demonstrations, and icons or physical symbols. Review what educational interventions, if any, the person had in school for suggestions.

➢ People with ASD are often very reliable workers, with a strong sense of duty and doing what is right. They also may have a strong desire to get along with their coworkers, even if their social skills are not strong.

➢ The person may be good at solitary activities, especially ones that require practice, endurance, visual accuracy, or repetition.

➢ The person may be very good at activities that involve attention to detail.

➢ Jobs that involve a lot of waiting or a lot of last minute changes in schedule or tasks might be a challenge

➢ Jobs in noisy, busy, or cluttered environments could be a challenge.

➢ Working directly with the public may be a challenge for the person. Contact with a small set of co-workers may be better.

➢ The social aspects of work are common challenges for people with autism and one of the main reasons they lose jobs.

➢ Supervisors and co-workers may need training on how to interpret the person's normal behavior. It is important that co-workers not misinterpret the person's normal behavior as rudeness or lack of cooperation. They should also be aware that an increase in unusual or "difficult" behaviors may mean the person is feeling stress of some type. The person may need to retreat from the situation for a while to a safe place, coworkers may need to adjust the environment for the person, or a supervisor may need to find out if something at home is upsetting the person.

➢ Individuals with a "fixation" (see Functional Description section and Theory of Mind above) on a particular topic, may retreat to talking about it when they are nervous, distressed, or do not know what to say or do. It may be a challenge for them to think of any other topic. To others this may seem like rudeness and self-

centeredness. Coworkers and supervisors may need training to view this as a type of behavioral communication about the person's anxiety.

➤ Interviewing for a job may be a challenge. For job-hunting situations, the person may prefer to concentrate on showing a portfolio of work or demonstrating work skills rather than depending on the social skills of interviewing. Alternatively, there may be a way of objectively rating the person's skill, such as a certification test or grade point average. This lets them sell their skills rather than their personality.

➤ Public transportation, such as a bus, may be very uncomfortable for the person because of both social and sensory issues. A bicycle, car, or car-pooling situation may be better. It is also useful to plan for backup transportation in case something goes wrong one day with the main transportation. The person should schedule some practice runs of the backup transportation so it is not a new and stressful event. The person may want to schedule days to use the backup system on a regular basis to keep in practice. The person may need to have an instruction card or sheet at home to help them remember about the backup arrangement.

➤ Handling more than one project or activity at a time may be a challenge for the person.

➤ Promotion from the initial job may be a challenge later on, especially if the promotion puts them in a management position.

➤ Office meetings can be challenging for the person, requiring additional supports:

- The social dynamics and skills of meetings are different from typical conversations

- The person may have trouble understanding what others are thinking or feeling

- Agendas may be difficult to understand

- Discussions often deviate from agendas

- The person may fixate on one aspect of the discussion ("Tomorrow is a holiday") and not process other topics ("We are facing budget cuts"), placing them out of sync with others in the meeting

- The meeting interrupts the usual routine of the day

- Possible Meeting supports might include:

  ▪ Social skills training on meetings (see social stories, comic book conversations, above)

  ▪ A co-worker to act as "mentor" or "translator" for the person during meetings

  ▪ Clear meeting agendas with a few main goals and objectives highlighted

  ▪ A slower pace for the meetings to allow processing time

  ▪ Summary follow-up notes on meetings

➲ Possible career options include

It is always best to talk with the person about their career preferences. The list below is just for brainstorming and is not intended to be exclusive or complete.

- Data Entry
- Engine Repair
- Graphic Arts
- Computer Programming
- Proof Reading
- Quality Control
- Inventory Stocking and Control
- Mail Room Services
- Book Keeping
- Banking
- Accounting
- Legal Research
- Laboratory Work
- Drafting, or Other Technical Work
- Library Services Aid (many corporations have private libraries and librarians on staff)
- Website Maintenance or Design
- Database Maintenance (updating of entries, monitoring for duplications or outdated data, etc.)
- Agricultural work, such as caring for crops and animals, or even lawn care or park maintenance, may match the preferences of some people with autism (routine, limited social dynamics, detail oriented)

Possible Job Accommodations

- A co-worker as mentor to help the person understand social situations and cues and workplace culture, or help "translate" instructions or comments from others

- Training for co-workers and supervisors about the person's characteristics, preferences, sensitivities, social skills, behavioral communication, etc.

- Social Coaching: training in social skills

- Gradual school-to-work transition, if possible

- Training done on site and first day activities which match the typical routine. People with ASD often look for immediate creation of new routines. A day or two of orientation and paperwork will be very confusing. Any prompts provided during training should be the same ones used during typical work routines

- A daily schedule prominently posted, with icons or pictures (even if reading skills are strong). The schedule should answer the questions "What am I doing?", "Why am I doing this?", and "What comes next?". Even individuals who are normally well anchored in their daily routine may have occasional "off" days when they lose track of these details and become confused

- A personal calendar or appointment book

- A PDA or smart phone with scheduling software, prompting software, etc.

- Advance warning of changes in routines, including a chance to practice new routines

- Extra support in times of high staff turnover or significant changes in work tasks

- Colored lines on the floor to identify areas of specific types of activities

- Physical icon objects to identify tasks or areas of specific activities

- Prominent prompts and environmental cues to signal areas of activity or transitions between activities during the day

- Social Stories for the workplace: a set of short stories or cue cards with information about what to do in different situations or explaining how people expect others to act in different situations (i.e. - "if I can't find a tool I need, I can ask the supervisor" [with a photo of the supervisor attached]; "if I run out of paper, I go to the copy room and ask for more"; a short paragraph on what happens when co-workers go out to lunch together, etc.)

- A work area with few distracting sounds, smells, or sights, possibly including the avoidance of fluorescent lights (which can hum or flicker)

- Sunglasses or tinted glasses to reduce light

- Headphones or earplugs to reduce sound levels

- White noise machine to mask distracting sounds

➢ Dividers or partitions to reduce sound/visual clutter or help visually define discrete work areas

➢ Freelance work with only brief social contact

➢ Concrete, well-defined work goals

➢ Concrete, well-defined feedback on quality of work

➢ A limited number of job assignments at one time

➢ Complex tasks broken into smaller sequences and displayed with diagrams

➢ Task checklists (with symbols) derived from a careful task analysis

➢ Flexibility to develop their own way of organizing a task

➢ Flexibility to organize their own workspace and maintain order there

➢ A safe place to retreat during times of stress

➢ Routine breaks, with a chance to be alone or do something the person finds relaxing (possibly including: moving around, swinging on a swing, or jumping on a small trampoline)

➢ Coaching on activities to do during breaks that match their interests, the setting, and the resources available

➢ A way to use writing, picture exchange, or gestures if speaking skills are weak

➢ A picture exchange system, communication board or choice board if speaking skills are limited

➢ A PDA or smart phone with augmentive communication or scheduling software

➢ Co-worker(s) designated to help alert the person to environmental cues like telephone rings, fire alarms, honking horns, etc.

➢ Plenty of space to move between furniture, machinery, etc.

➢ Work space with a limited number of things that could be knocked over by accident

➢ Assistive technology for tasks involving fine motor skills

➢ Extra time to think and process when receiving instructions, asking questions or answering questions

➢ Self-Assessment / Self-rating scale (depending on functional abilities of client) to improve self awareness and reflection of performance

● *Portable Electronics Technology*

As of this writing (2009), the field of software designed to support people with ASD and related disabilities is just beginning to expand. A few companies have produced software for palmtop computers for a number of years, but the high cost of those devices limited the market and the number of options.

However, the recent, dramatic spread of inexpensive personal digital assistants and smart phones is changing that situation. Several Augmentative and Alternative Communication (AAC) programs (which "speak" a person's message when the person presses icons on a screen) have been adapted to these devices. In addition, a small number of companies have begun developing scheduling, prompting, and countdown software for iPhones and other smart phones. The field is changing so rapidly that any listing of specific sources and products will be quickly outdated. But a quick internet search should provide current information.

Emerging Issues

➢ Employment characteristics of adults with ASDs

➢ Best practices in employment services for adults with ASDs

➢ Best practices in independent living for adults with ASDs

➢ Environmental contributing causes of ASDs

Additional Information Resources

There is very little practical or research information about the employment and independent living needs of adults with ASD. Our program at the University of Missouri will be locating or generating resources as we are able.

➢ **Autism Works**, Disability Policy and Studies at the University of Missouri: ***www.dps.missouri.edu***

➢ **Vocational Rehabilitation Service Models for Individuals with Autism Spectrum Disorders**. A research project to identify best practices in vocational rehabilitation for people with ASD, this site also acts as a clearinghouse for a variety of adult ASD resources: ***www.autism.sedl.org***

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Adult Autism & Employment
A Guide for Vocational Rehabilitation Professionals

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