

**Navigating and Expediting Access to Social Security for Transition and Late Diagnosed Adults**

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**The Missing Link:  
The Connection Process®**

- How does **the individual** experience their unique expression of ASD?
- How do **others** experience the ASD?
- What can be done to **bridge the void** between?
- How does disclosure **level the playing field?**
- How does one use accommodation, adaptation and modification to **maximize productivity and maintain personal wellness?**
- How does all of this sync together to insure the **maximum productivity balanced with the highest quality of life?**

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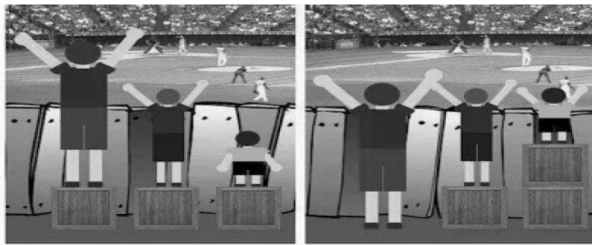
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**Fair Versus equal**



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## Stop the Entitlement Shaming!



- Better their money than yours!
- People age out of parental insurance
- No one should have to ask for \$ for a movie or DVD
- This is fair—not equal and that's okay!

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- ❖ You don't **outgrow** your accommodations.
- ❖ You don't **outgrow** your autism.
- ❖ You grow **INTO** it.



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## SSI/SSDI: 40 HOURS A WEEK

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| <ul style="list-style-type: none"><li>• Social Security Income</li><li>• Income dependent</li><li>• Under or never employed</li><li>• Must spend what's earned</li><li>• Savings limited (\$2000)</li><li>• If parent is on SSDI, retired, or deceased, the individual may be eligible to draw from that other account</li></ul> | <ul style="list-style-type: none"><li>• Social Security Disability Income</li><li>• Not income dependent</li><li>• Was employed</li><li>• Can have savings</li><li>• Money comes from money previously designated for retirement</li></ul> |
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## FIND ADULT PROVIDERS

- Current psychological that is norm-referenced for adult models (high school duties)
  - Working memory
  - Processing speed
  - Learning disabilities
  - Executive functioning
  - IQ
  - Statement of need for work related skills and/or training for employment
  - Depression, anxiety, behavioral needs
  - Independent living skills
- Speech/language/communication evaluation
  - Expressive, receptive, pragmatic, social skill capacities
- Occupational therapy evaluation
  - Sensory
  - Motor (fine/gross)
  - Stamina
  - Strength
  - Standing/sitting

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## How do we decide?

- Representative Payee
- “Trial” money
- Autonomy
- Financial breathing room for families and individuals
- Medical benefits after aging out
- Easy access to Vocational Rehabilitation\*
- Free banking with direct deposit
- Fears:
  - He’ll spend all his money
  - She could be taken advantage of
  - He’ll be lazy (dependent and never work)
  - He can’t work if she gets SSI
  - Her trust fund will disappear
  - He will never get it.
  - We will pay an attorney a lot of money.

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## How does *the individual* experience their unique expression of ASD?

- **MOBILITY**
- The physical and psychological ability to move about from place to place inside and outside the home compared to people with normal mobility. This includes travel to and from usual destinations in the community for activities of daily living, training, or work.
- READ A MAP?
- USE A GPS?
- DRIVE?
- GIVE DIRECTIONS TO DRIVER?
- NAVIGATE CAMPUS?
- KNOW ADDRESS?
- MOTOR FATIGUE?
- ANXIETY?

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How does ***the individual*** experience their unique expression of ASD?

- **INTERPERSONAL SKILLS**
- The individual's ability to establish and maintain personal, family and community relationships as it affects (or is likely to affect) job performance and security.
- ASK DIRECTIONS?
- FOLLOW DIRECTIONS?
- EXPRESS NEEDS?
- RELATE WITH CO-WORKERS?
- HAVE SCRIPTS TO CONVEY UNDERSTANDABLE EXPLANATIONS?
- VULNERABILITY?

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How does ***the individual*** experience their unique expression of ASD?

- **COMMUNICATION SKILLS**
- The ability to effectively exchange (give and receive) information through spoken words or concepts (writing, speaking, listening, sign language, or other adaptive methods). Limitations may occur because of physical, emotional, or cognitive impairments.
  - EXPRESSIVE: CAN I EXPRESS MYSELF?
  - RECEPTIVE: HOW DO I BEST RECEIVE INFORMATION?
  - PRAGMATIC: HOW DO I MANAGE SOCIAL 'WINDOW DRESSING'?
- FRUSTRATION?
- NEED INFO BROKEN DOWN?
- NEED TO HAVE EXPECTATION DEMONSTRATED?
- DO I UNDERSTAND THE FIRST TIME I AM TOLD?
- WILL I LOSE LANGUAGE UNDER PRESSURE?
- WILL I BE KIND AND UNDERSTANDING TO OTHERS?

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How does ***the individual*** experience their unique expression of ASD?

- **SELF-DIRECTION**
- The ability to independently plan, initiate, problem solve, organize, or carry out goal-directed activities related to self-care, socialization, recreation, and work. This does not relate to the worth of an individual's goals or plans, but the capacity to know, plan and act on a course of action based on personal values or goals.
- CAN THEY WORK INDEPENDENTLY?
- DO THEY KNOW WHEN THEY ARE IN TROUBLE?
- WILL THEY FEAR DISCLOSURE?
- WILL THEY FEAR ADMITTING THEY NEED ASSISTANCE?
- WHAT INTENSITY OF SUPPORT WILL BE REQUIRED?

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How does ***the individual*** experience their unique expression of ASD?

- **SELF-CARE**
  - The ability to manage self or living environment (i.e., eating, toileting, grooming, dressing, and money management), as they affect an individual's ability to participate in training or work-related activities. This includes an individual's management of any special health and safety needs which exist; for example, medication management. Limitations may occur because of physical, cognitive, or emotional impairments, and could extend to all tasks or only specific tasks.
- HYGIENE
- TIME MANAGEMENT
- PLANNING SKILLS
- EXECUTIVE FUNCTION IN REAL TIME APPLICATION
- MEDICATION
- MONEY MANAGEMENT
- SELF-WAKING, REGULATING OF NON-DAILY TASKS

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How does ***the individual*** experience their unique expression of ASD?

- **WORK TOLERANCE**
  - Capacity to effectively and efficiently *sustain* physical, cognitive and/or psychological demands of a job. Limitations may be due to physical disability, stamina/fatigue, effects of medication, or psychological factors.
- PRESSURE TO PERFORM
- TIMED TASKS
- CAPACITY TO MAINTAIN FULL DAY (INCLUDING PREPARING FOR AND RECOVERING FROM A FULL DAY OF WORK)
- STANDING, SITTING, WALKING, SOCIAL ENGAGEMENT
- TRANSITION TO NEW TASKS, CHANGING TASKS

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How does ***the individual*** experience their unique expression of ASD?

- **WORK SKILLS**
  - The ability to do specific tasks required to carry out job functions as well as the capacity to benefit from training in the necessary skills.
- KEYBOARDING
- MAKE CHANGE
- CALCULATOR
- TASK COMPLETION
- TASK TRANSITIONS
- ABILITY TO USE SKILL TRAINING
- NARROW SKILL CAPACITY
- CAPACITY TO WORK FOR A VARIETY OF INDIVIDUALS\*

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How does ***the individual*** experience their unique expression of ASD?

• **TRAUMA**

- School
- Prior work trials
- Home situations
- Community harassment
- Late diagnosis
- Maltreatment
- PTSD



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**SAMPLES**

• **MOBILITY**

- Despite being 19 years old, I have not attempted to secure my driver's license. I experience outward anxiety even when someone else is driving so I know that I could never do it. My brother who is eight years younger than I is often my directional support.
- Any change in route or unpredicted change in route is incapacitating for me. Even if someone else is driving, I panic when we don't go the same way as usual. So I can imagine that when driving, if there were a roadblock or high water, I would just sit in my car and cry. If I were on public transportation and a change happened, I would likely have the same response. When I am a passenger in a car, I get nervous so I read to distract myself so I can't see where we are going.

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**SAMPLES**

• **INTERPERSONAL SKILLS**

- I have a lot of trouble with boundaries. My extended family members do not very understand, and sometimes when I say things that are not appropriate, they get angry back. I have black and white thinking and need people to follow the rules. It's hard for me to see other circumstances that could be impacting situations and without knowing those circumstances; I can jump into a situation where I am not needed, where it is not my business or where I should have just kept to myself. I am very direct and blunt and have offended people. My parents do a lot of translating especially between my siblings and I, and with my extended family.

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## SAMPLES

- **INTERPERSONAL SKILLS**

- At my volunteer job, I have had issues. On two occasions potential adoptive people came to see the pets and when they found out that they would have to follow our strict rules to adopt or pay a fee, they got really irritating. I was direct and told them exactly what I thought. My supervisors thought I was rude and they were not happy with me. I knew I had lost it and I was embarrassed by what had happened. I didn't go back for a long time. Later I did apologize. Now I am afraid that what happened in these situations could happen again and still volunteer at the shelter because it's more predictable but I don't want to go back to the stores on the weekends.

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## SAMPLES

- **COMMUNICATION SKILLS**

- Client is easily frustrated in social exchanges that he feels are a waste of his time and as such, gets loud when frustrated. His ability to communicate his needs is very limited. He speaks in bullet points and harsh abbreviated, phrases. Sometimes he does not ask enough qualifying questions and gets only parts of the needed information. He would get angry and storm out. He would raise his voice and is often perceived by others as threatening although he has never acted violently at school.

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## SAMPLES

- **SELF-CARE**

- I don't manage my own money. I have trouble visioning what I need and making lists so that things last. When I tried college, I could not figure out how to make my money last or how to anticipate what I needed. I could do the basic math of a checking account but I can't figure out the in and out of it all; like when the debit says I have money that I don't have anymore.
- I often don't know that my body is hungry until I am ravenous and then I am too hungry and impatient to wait for the cooking. I also have trouble getting the dishes to the dishwasher afterward, although that is a work in progress. (SENSORY too)

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## SAMPLES

- **WORK TOLERANCE**
- He is very distractible however, routine tasks would be very boring and he would quickly exhaust of any such tasks. Still, his ability to learn a task would depend on a "tell me, show me, watch me" sequence of instruction and it would have to be rehearsed repeatedly. It's likely that this needed repetition would frustrate him. His work limit is 20-30 minutes unless extremely highly motivated by special interests.

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## SAMPLES

- **WORK SKILLS**
- Despite repeated efforts, Client could not learn to keyboard. Due to physical limitations related to low muscle tone, client can't stand for long periods of time. Client must be able to sit in somewhat peculiar positions during seated work time and may require an ergonomically fitted chair in any work environment. Even then, frequent movement breaks will be required. He will not be able to sustain either a standing or sitting work environment for more than 20 minutes at a time and likely, only 3-4 total hours per day, based on his break schedule from high school.

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## SAMPLES

- **EXECUTIVE FUNCTION**
- Client struggles with multiple step directions given verbally. Although he does do better in writing, distraction and a lack of focus can keep even written directions from being hard for him to follow. His fatigue also negatively impacts his capacity to focus in a conversation long enough to gather specific information.
- Additionally, Client struggles with non-explicit directions. A simple "clean your room" must be redirected to at least 15-20 detailed steps. He can't follow abstract, non-direct instruction either. This negatively impacted academics as well.

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## SAMPLES

### • ANXIETY/PHOBIAS

- I have a hard time sleeping at night when I am alone. I wake up with nightmares and can't go back to sleep because my heart is racing and I feel like I can't breathe and I can't stop thinking about scary things. I think I realize that's part of what happened at college when I couldn't sleep by myself, got depressed, and then couldn't go to my classes and couldn't face my teachers and got so far behind I gave up. I think I got traumatized when I was little and saw a movie about aliens kidnapping a kid and cutting his head open and they showed the kid's brain. I was scared of aliens at nighttime and for a long time I'd go in and sleep in my mom's room at night because I was so scared. I continue to experience fear when alone at night, even at 24. I know it's not logical because nothing bad has ever happened to me, but I can't stop it.

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## SSDI PASS Plans

- VR Self-employment initiative
- Requires a full, viable, competitive business plan
- Will take a long time and a lot of work
- SSDI goes into business account making you eligible for SSI. Must be able to demonstrate you can live on @\$889 a month
- Can be used for some equipment; should get most \$ from VR for start up
- Only used cars

### Center for Understanding



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## What's Next?

- All of this is just to fill out the forms.
- Have all appropriate service providers give you copies of documents they will provide.
- Encourage them to use the format you now have. (Consistency counts!)
- Take all hard copies, with bulldog clips, to the neighborhood office. Get a receipt.
- You will be denied.
- Secure updated files when they ask for more info. Basically, the files should say, nothing is improving.
- Update client report.
- Submit.
- Decide if you want to use an attorney at this point.

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## What's Next?

- FOOD STAMPS and other FINANCIAL NEED ISSUES
  - You can pay bills directly, but you can't give the client the money to pay them.
  - If you can agree that you do not secure food together, your recipient will likely be eligible for food stamps. This helps the SSI case.
  - When back pay arrives, burn it reasonably and quickly.
  - Get rep payee status
  - Guardianship helps
- First check may be low. Demonstrate expenses
  - Pay off of car
  - Receipt worthy pay back of personal debt
  - Rent (they don't pay you rent-they pay part of the mortgage)
  - Utilities (same deal)
  - Medical
  - Dental
  - Credit card debt

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