Developing effective self-determination skills in youth with ASD
Perspectives from the autism spectrum and an OT practitioner/researcher

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A little about me...
WHERE DOES AUTISM COME FROM?

Where oh where did this autism come from?
Oh where oh where can it be?
With mysteries cut long and eye contact cut short?
Oh where oh where can be from?

A LITTLE ABOUT ME

Introduction

The Autism Bomb — NOT
Reading the funnies?
At the end of the session, we hope you will be able to:

- **Discuss** the concept of self-determination, its measurement, and literature related to self-determination in youth with autism spectrum disorder (ASD).

- **Identify** actions therapists, parents, and other professionals can take in implementing approaches to fostering self-determination for youth with ASD.
Outline for Short Course

1. What is self-determination?
2. Why is self-determination important?
3. What do we know about self-determination?
4. How do we know when someone has improved their self-determination?
5. VIDEO – individuals talking about self-determination
6. Personal example
7. Clinical examples of self-determination tools to assess self-determination
8. Clinical examples of ways to embed self-determination teaching and skills into many practice settings
“You need to ask yourself, Am I a pecan or a pecan’t?”
What is Self Determination?

- Turn to your partner and discuss what you think this means.
- Write your ideas around the room OR
- Post to www.nearpod.com

“I am not what happened to me, I am what I choose to become.”
—Carl Gustav Jung
What is Self Determination?

- Knowing and believing in yourself
- Knowing what you want in the future AND making plans to achieve those goals
- Knowing and asking for the supports you need to achieve your goal
- Having the ability to monitor and regulate one’s own action
- Characteristics of a person that lead them to make choices and decisions based on their own preferences and interests
Why is Self-Determination Important?

❖ Greater self-determination is associated with better adult outcomes for youth with disabilities

❖ Essential characteristics of self-determined individuals (e.g. autonomy, self-regulation, psychological empowerment, self-realization) predicts higher Quality of Life

❖ Youth with greater self-determination are significantly more likely to report higher community access and employment a year after high-school than youth with lower self-determination

◊ Shogren, Wehmeyer, Palmer, Rifenbark, Little (2015)
◊ Wehmeyer & Schwartz (1997)
◊ Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo, & Walsh (2005)
What Do We Know about Self-Determination?

- Self-determination is developmental

- Self-determination is changeable
  - Self-determination is more strongly related to instruction and opportunities than personal characteristics (Lee et al., 2010)
    - Wehmeyer et al (2011)
    - Oswald, Winder-Patel, Ruder, Xing, Stahemer, & Solomon (2017)

- Self-determination is measurable

Note: This Literature pertains to samples with a variety of youth with disabilities
What Do We Know about Self-Determination?

- Evidence-based approaches exist to support youth in developing self-determination

  - ACCESS Program (Oswald et al., 2017)
  - ChoiceMaker (Martin, Marshall, Maxson, & Jerman, 1996)
  - Self-Advocacy Strategy (Van Reusen, Bos, Schumaker, & Deshler, 1994)
  - Self-Determined Learning Model of Instruction (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000)
  - Steps to Self-Determination (Field & Hoffman, 1996)
  - Whose Future Is It Anyway? (Wehmeyer et al., 2004)

Note: This Literature pertains to samples with a variety of youth with disabilities
What Do We Know about Self-Determination in Autism?

- **Self-determination is lower among youth with autism spectrum disorders**, as compared to youth with intellectual disability, and youth with learning disabilities (Chou, Wehmeyer, Palmer, Lee, 2014)

- WHY? Unknown. Potential Reasons:
  - **Capacity**
    - Self-determination is associated with social-skills
      (e.g. Nota, Ferrari, Soresi, & Wehmeyer, 2007)
  - **Opportunity**
    - Not given a chance to practice making decisions for self in home, school, community

- Parents, educators, other providers should be aware that supports provided to improve self-determination should be tailored
**How** do we know when someone has improved in their self-determination?

A person will demonstrate self-determination through actions, such as:

| • Making choices based on free will without interference | • Accurately evaluating their strengths |
| • Proactively solving problems | • Ability to be disciplined and solve problems |
| • Taking responsibility for oneself | • Engaging in self-reflection /self-evaluation |
| • Having the self-confidence to act | • Setting their own goals and then seeking to accomplish them |
| • Directing their own life | • Believing that achievements are under their control |
| • Knowing their own strengths and weaknesses (challenges) |  |
How do we know when someone has improved in their self-determination?
Example: Deciding to use person or identity first language

- Professionals have a responsibility to support the self-determination of individuals, and inquire what preferences they have.


A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 4

<table>
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<tr>
<th>AGE</th>
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<th>4</th>
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<td></td>
<td>Typical development</td>
<td>Autism bomb hits environment</td>
<td>Strong autistic tendencies &amp; psychotic</td>
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<td>Turn over at 8 days</td>
<td>Withdrawal from environment</td>
<td>Early intervention from parents who refute recommendations for removal from home</td>
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<td>Rapid physical and motor development</td>
<td>Tantrums</td>
<td>Self Awareness</td>
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Self Awareness
How do we know when someone has improved in their self-determination?

Three valid and reliable measures have been examined for use in youth with autism:

1. **The Arc’s Self-Determination Scale** – Student self report
   (Wehmeyer et al., 1995; Wehmeyer, Shogren, Palmer, & Lee, 2014; Chou, Wehmeyer, Palmer, & Lee, in press)

   72 items, 4 domains:
   - Autonomy (32 items)
   - Self-Regulation (9 items)
   - Psychological Empowerment (16 items)
   - Self-Realization (15 items)

   • Normed on over 500 individuals with disabilities
How do we know when someone has improved in their self-determination?

2. **The AIR Self-Determination Scale (AIR)** – Student, Parent, Educator versions available
   (Wolman, Campeu, Dubois, Mithaug, & Stolarski, 1994)
   - 24 items with 2 subscales:
     - Capacity ("Things I Do", "How I Feel")
     - Opportunity (perceptions of opportunity)
How do we know when someone has improved in their self-determination?

3. Seven Component Self-Determination Skills Survey (Carter et al., 2013)—less studied

- Two domains: **Performance** and **Importance**
  - Performance Scale:
    - Choice-making,
    - decision-making,
    - goal-setting,
    - problem-solving,
    - self-advocacy/leadership,
    - self-awareness/self-knowledge,
    - self-management/self-regulation
  - Importance Scale
How do we know when someone has improved in their self-determination?

4. Self-Determination Inventory-Student Report (SDI:SR)—less studied

- Designed for 13-22 years of age
- 20 minutes
- Online, has built in accommodations
- Assesses three areas
  - Volitional action
  - Agenic action
  - Action-control beliefs

- [www.self-determination.org](http://www.self-determination.org)
Example of Arc Items

### Autonomy

**Question 22.**

**I do school and free time activities based on my career interests:**

- I do not even if I have the chance
- I do sometimes when I have the chance
- I do most of the time I have the chance
- I do every time I have the chance

### Self-Regulation

**Question 33.**

**Beginning:** You are sitting in a planning meeting with your parents and teachers. You want to take a class where you can learn to work as a cashier in a store. Your parents want you to take the Family and Child Care class. You can only take one of the classes.

**Middle:** _______________________________
_______________________________
_______________________________
_______________________________

**Ending:** The story ends with you taking a vocational class where you will learn to be a cashier.
Example of Arc Items

**Psychological Empowerment**

Item 43:
- I tell others when I have new or different ideas or opinions… or
- I usually agree with other peoples’ opinions or ideas

Item 49:
- It is no use to keep trying because that won’t change things… or
- I keep trying even after I get something wrong.

Item 58: I do not feel ashamed of any of my emotions.
- Agree
- Disagree

Item 61: I can like people even if I don’t agree with them.
- Agree
- Disagree

Item 65: I know what I do best.
- Agree
- Disagree
### Examples of AIR Items

#### Things I Do – Total Items 3 + 4

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<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
<th>Always</th>
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<td>1</td>
<td>2</td>
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<td>5</td>
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#### What Happens at School – Total Items 1 + 2

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<th>Almost Never</th>
<th>Sometimes</th>
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<td>5</td>
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Check In With a Neighbor-- Can you....?

☐ **Discuss** the concept of self-determination?

☐ **Identify** how you would know if someone improved in their self-determination?

☐ **Name** literature related to self-determination in youth with autism spectrum disorder (ASD)?
How to Improve Self-Determination

Let’s Share Perspectives & Roles:

- Self-Advocate
- Provider

Go confidently in the direction of your dreams! Live the life you’ve imagined.

-Thoreau
Tips for Addressing Self Determination

- Students need to be directly taught skills that lead them toward becoming self-determined individuals.

- Acquiring the characteristics that lead to self-determination is a developmental process that begins in early childhood and continues through adulthood.


ASPIRE Parents: https://youtu.be/h5WQArT-CtQ

Your Voice: http://youtu.be/BLVHj-OhJfw
Tips for Providers in Addressing Self-Determination

- **Step 1: Presume competence**

  - Ensure individuals you work with have an **opportunity to make choices** in their home, school, and other environments.
  - All individuals have a right to make choices and communicate those choices.
  - Promote and advocate for your client’s ability to be present at meetings or other events where decisions are made about them and their future.
Tips for Providers in Addressing Self-Determination

- **Step 2: Identify & discuss strengths and opportunities in their life to foster psychological empowerment**
  - Evaluate and understand your client’s strengths
  - Help your client understand and explore their strengths
    - Therapy activities should **not** just work on things that are weaknesses
  - Set high expectations
  - Use positive language
Tips for Providers in Addressing Self-Determination

- **Step 3: Identify & discuss personal goals to increase Autonomy & Psychological Empowerment**
  - E.g. Start of program: “My goal is to get others to like me”
  - E.g. End of program: “My goal is to make new friends”
  - Collaborate with your client to identify what those goals might be.
  - Some people may need help identifying realistic and feasible goals. Instead of saying their goal is not feasible, help them identify more feasible short term goals that could be accomplished.
Tips for Providers in Addressing Self-Determination

● **Step 4: Develop a plan for accomplishing goals, including acquiring skills that are needed to be successful**
  ○ Self-regulation
  ○ Help person move from external locus of control to internal locus of control
  ○ Focus skill development on those things that could impact their goals
  ○ Use scaffolding and upgrading/downgrading to collaborate on small steps to reach goals
    ○ E.g. Goal is to make new friends--Identify groups where comfort level is high (e.g. robotics class), and set goals to sit with a new person every other week. Work on skills in social conversation.

● **Step 5: Ensure others are also on board—support circle is necessary**
  ● Create and foster opportunities for other networks to be aware of and support goals and skills.
Case: Scott, a 16 year old with autism

Setting for Intervention
- School for students with learning differences and takes two classes at local high school
- Strengths: highly verbal, social, polite, skill with computers, spatial navigation, and maps

Measurement
- AIR Self Determination Scale (AIR), ARC Self Determination Scale (SDS)
- Qualitative interview
- Measurement at week 0 (Pretest 1), week 9 (Pretest 2), week 20 (Post test)

Baseline (wks 0-9)
- Usual Care (UC) OT: pre vocational/social skills group, OT/Speech Language Pathology (SLP) collaborative sessions & consultations

Intervention (wks 10-19)
- 40 min/wk individual OT focusing on student-identified goals
- Strengths based planning meeting with student-identified stakeholders
Scott’s Goals—Qualitative

Pretest Week 0 (Pretest1)—To get places by car, bus; ‘to get people to like me’

Pretest Week 9 (Pretest 2)—To work at AAA; to get my learner’s permit, ‘to get people to respect me and for me to be respectful’

Posttest Week 20—Learn how to get a job for the summer, learn how to decide on classes for next year, ‘to make new friends’
What Happened During Sessions?

**Fostered autonomy & volitional action**
- Supported Scott in identifying opportunities for choice at school and at home

**Encouraged self-realization**
- Discussion with Scott regarding strengths, goals, beliefs about self, interests

**Ensured opportunities for self-regulation and action**
- Provided learning opportunities for decision-making with support
- Facilitated learning activities to plan action steps to reach goals in collaboration with Scott’s preferred team

**Fostered empowerment through focus on strengths**
- Helped Scott plan strengths-based transition meeting
- Facilitated Scott’s ability to lead the meeting to accomplish goals

**Outside of School**
1. Meeting with mom
2. Discussion with transition coordinator
3. Discussion with other teachers
What do you want to be when you grow up?

Life after high school may be several years away or just around the corner, but it’s not too early to start imagining your future. The Career & Life Explorer is designed to help you plan that future. It can help you:

- Identify key interests, values, and abilities
- Define your ideal job
- Consider education, training, and work options after high school
- Explore more than 100 occupations

Just follow the steps and answer each question. This is not a test, so there are no right or wrong answers. When you are ready, open to the first step and get started!
Items that Reflected Change in Psychological Empowerment

I tell others when I have new or different ideas or opinions Versus
I usually agree with other people’s opinions or ideas

I tell people when they have hurt my feelings Versus
I am afraid to tell people when they have hurt my feelings

I can make my own decisions Versus
Other people make decisions for me
Qualitative data about IEP versus the student-led meeting focused on strengths and student goals

<table>
<thead>
<tr>
<th>Scotty’s Responses Regarding His Involvement in Transition Meetings (IEP versus SBPM)</th>
<th>IEP Meeting</th>
<th>Strengths-Based Planning Meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>How involved were you?</td>
<td>“Not really involved that much”</td>
<td>“50%, I physically led the meeting.”</td>
</tr>
<tr>
<td>Who planned the meeting?</td>
<td>“My mom and case manager”</td>
<td>“Me, with help.”</td>
</tr>
<tr>
<td>Do you prepare?</td>
<td>“No”</td>
<td>“Yes, I told you things that interested me, invited people, wrote notes for me and the agenda, role played the meeting.”</td>
</tr>
<tr>
<td>Do you go at the beginning?</td>
<td>“No they called me in…when they are done with me, they are done with me, and I go back to my afternoon.”</td>
<td>“Yes, I was early.”</td>
</tr>
<tr>
<td>Did you feel comfortable sharing?</td>
<td>“I don’t really feel comfortable.”</td>
<td>“At the beginning, no, once I continued, yes.”</td>
</tr>
<tr>
<td>Do you think you made the decisions?</td>
<td>“No, the adults in the room do.”</td>
<td>“A little bit, I mean you guys helped me.”</td>
</tr>
<tr>
<td>Additional Thoughts?</td>
<td>“I was nervous and shy but… I have matured to where I could do some stuff.”</td>
<td>“My mom was REALLY proud of me!”</td>
</tr>
</tbody>
</table>

Results of this pilot single-case study suggest that the Arc SDS\textsuperscript{8} results aligned with student expressed outcomes regarding future goals.
How will you Address...

- Autonomy?
- Self-Realization?
- Psychological Empowerment?
- Self-Regulation?

Share your idea on nearpod: [www.nearpod.com](http://www.nearpod.com)
Can You...?

- **Discuss** the concept of self-determination, its measurement, and literature related to self-determination in youth with autism spectrum disorder (ASD).

- **Identify** actions therapists, parents, and other professionals can take in implementing approaches to fostering self-determination for youth with ASD.
References for Existing Self-Determination Curricula

Self-Determination.org


References of Measurement Tools


Article which examines these two measures:
Other References


Links to Videos and Other Resources

https://vimeo.com/45742131
http://www.imdetermined.org/
http://www.imdetermined.org/resources/detail/tips_for_parents
http://www.imdetermined.org/parents/videos/
http://ngsd.org/everyone/what-self-determination
https://www.autismspeaks.org/docs/family_services_docs/SelfDetermination.pdf
http://www.ocali.org/project/tg_aata/page/self_determination

Articles: