THE PATH TO SELF-DETERMINATION (& THEN SELF-ADVOCACY)

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IT'S ABOUT THE FOUNDATION!
DEVELOPMENT OF SELF: I AM...

Not ears
Not an audiogram
Not a “freak”
Not “retarded”

Just a person like everyone else!
DEVELOPMENT OF IDENTITY: LEARNING AND ACCEPTING WHO I AM

Who am I?
How am I different?
Why am I different?
When does my difference become a challenge?
What should I do?
What am I willing to do?
TRANSFORMING HOW DISABILITIES ARE PERCEIVED

**Medical Model**
Disability is a deficiency:
- Located within the person
- Disability is negative and should be ameliorated

Remedy is individual’s problem
Agent of Remedy: Health care professional

**Social Model**
Disability is a difference:
- Located between the person and society
- Disability is neutral in life’s context

Remedy is negotiated interaction with society
Agent of Remedy: Person and people with whom the person interacts

What’s wrong with the person? What does the person need?
THE PATH MAY BE CIRCUITOUS

Identity

Self-Determination

Self-Advocacy

Personal Responsibility

Self-Determination

Self-Advocacy

Identity
SELF-DETERMINATION: WHAT DOES IT MEAN?

The attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference (Wehmeyer, 1992).

A person’s actions are self-determined if:

- He/she acts autonomously
- Regulates his or her behavior
- Initiates and responds to events in a manner indicating psychological empowerment, and
- Behaves in a manner that is self-realizing (Wehmeyer, Kelchner, & Richards, 1996).

e.g., The person acts in ways that make positive use of knowledge and understanding about his or her own characteristics, strengths and limitations.
**DEVELOPMENT OF SELF-DETERMINATION (SD): THE RIGHT TO DIRECT ONE’S OWN LIFE**

- Students with SD skills have a stronger chance of being successful in making the transition to adulthood, including employment and independence.
  - One year post-graduation, students with higher levels of SD in high school were more likely to be living outside the home, employed for pay and earning more per hour than those with lower levels of self-determination. (Wehmeyer & Schwartz, 1997)
  - SD in students with disabilities was a significant factor in transition planning particularly self-regulation and self-awareness/self-knowledge (Wehmeyer et al, 2007)

- Components of Self-Determination (University of IL at Chicago National Research & Training Center, 2002)

<table>
<thead>
<tr>
<th>Free will</th>
<th>• Personal agency</th>
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<tr>
<td>Civil and human rights</td>
<td>• Self-direction</td>
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<tr>
<td>Freedom of choice</td>
<td>• Individual responsibility</td>
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<td>Independence</td>
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A MORE PRAGMATIC DEFINITION: (MARTIN & MARSHALL, 1996)

A self-determined person:

- Sets goals
- Makes decisions
- Sees options
- Solves problems
- Speaks for oneself
- Understands what supports are needed for success
- Knows how to evaluate outcomes

Self-determination is not achieved solely because a person has certain knowledge and skills; they must also be supported by key persons and institutions in that person’s life who provide a context conducive to self-determination. (Deci & Deci & Ryan, 1985, 2000; Ryan & Deci, 2000)
ROADBLOCKS TO SELF-DETERMINATION

Roadblocks to Self-Determination

- Difficulty acknowledging and/or accepting a difference
- Unprepared to disclose their disability
- Choose not to disclose
- Wait to disclose AFTER they have significant problems
- Anxious about a "new beginning" and do not want to be labeled
- Waiting too long to start

Examples of Problems - Audiology

- SD building blocks are missing
- Absent of peers, social integration opportunities
- Students who are not part of the selection of technology and/or supported to use their technology
- Self-advocacy attempts that are thwarted by their teacher
- Parents who deny the need for, or do not support, hearing instrument technology
- School cultures that are not flexible to meet individual needs of students
- Technology that does not work
PARENTS’ THOUGHTS ON SELF-DETERMINATION:
“WHAT DOES SD MEAN FOR YOU AND YOUR CHILD?”
BEYOND THE FITTING APPOINTMENT: PATTERNS OF HEARING AID AND FM SYSTEM USE IN THE CLASSROOM
DAVIS, GUSTAFSON, HORNSBY, & BESS (AAA, 2015)

- N=26, grades 1-7
- 22/26 were consistent hearing aid users (85%)
- 6/22 (36%) of these were never observed using FM
- Personal & CADS
HAT USE: WHAT IS THE PROBLEM?

Student?
School/Teacher/Staff?
Technology?
Support?
Knowledge?
Orientation and Training?
### Table 1

Opinion: Main Reasons FM System is Not Used Consistently

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<tr>
<th>Reason</th>
<th>Gen Ed Tchrs</th>
<th>Sp Ed Tchrs</th>
<th>TSLI</th>
<th>Other</th>
<th>Parent</th>
<th>Audiologist</th>
<th>Student</th>
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<tr>
<td>Social</td>
<td>45</td>
<td>60</td>
<td>57</td>
<td>50</td>
<td>60</td>
<td>44</td>
<td>56</td>
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<tr>
<td>Mechanical</td>
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<td>13</td>
<td>14</td>
<td>8</td>
<td>20</td>
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<tr>
<td>Comfort</td>
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<td>7</td>
<td>14</td>
<td>17</td>
<td>0</td>
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<td>14</td>
<td>25</td>
<td>40</td>
<td>22</td>
<td>11</td>
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<tr>
<td>Benefit</td>
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<td>0</td>
<td>14</td>
<td>0</td>
<td>20</td>
<td>11</td>
<td>44</td>
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<tr>
<td>Convenience</td>
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<td>0</td>
<td>0</td>
<td>17</td>
<td>0</td>
<td>22</td>
<td>22</td>
</tr>
</tbody>
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MDHC TEEN SURVEY: FM USE
SANDRA GABBARD, PH.D., DIRECTOR OF
AUDIOLOGY, UNIVERSITY OF COLORADO
HOSPITAL & ZACHARY LAFRATTA, LEND AUD.
FELLOW, UNIVERSITY OF COLORADO HOSPITAL

Written Survey

28% use personal FM

58% did not know their type of hearing loss,

39% did not know degree of HL

22% did not know how to describe their general hearing loss

I haven't like it in the past but I might try something new.
I wear it because it is in my IEP.
Never tried it, and I don’t want to.
I haven't used it but tell me more.
I love my FM
Relationship of motivation to internalized ideas and values:

• Internalized perspectives impact behavior change (Ridgeway)
  ○ Autonomous motivation, where participation is a SD behavior, promotes the internalization process to adoption a behavior.
  ○ Controlled motivation, where participation stems from external pressure, sense of guilt or obligation.

• Conclusion: Hearing aid use satisfaction was positively associated with autonomous motivation.
STRATEGIES AND SOLUTIONS
1. COUNSELING/HABILITATION

Self-Determined Learning Model of Instruction
(Wehmeyer, 1999)

Phase 1: Set a Goal
1. What do I want to learn?
2. What do I know about it now?
3. What must change for me to learn what I don’t know?
4. What can I do to make this happen?

Phase 2: Take Action
5. What can I learn from what I don’t know?
6. What could keep me from taking action?
7. What can I do to remove these barriers?
8. When will I take action?

Phase 3: Adjust Goal or Plan
9. What action have I taken?
10. What barriers have been removed?
11. What has changed about what I don’t know?
12. Do I know what I want to know?
PROBLEM SOLVING SEQUENCE EXAMPLE

1. Identify the problem
   - Student believes that all communication and instruction is received
   - Work with student to see problem and identify situations when communication is missed: FLE, CPQ, SAC/SOAC

2. Identify barriers to solving the problem
   - Unwilling to explore problem
   - Unwilling to self-disclose
   - Wants to continue current status

3. Identify consequences of each solution
   - Discuss challenges of no change and benefits of improving access
   - Discuss options for improving access
TIPS FOR PROMOTING SELF-DETERMINATION
NATIONAL CENTER ON SECONDARY EDUCATION & TRANSITION
WWW.NCSET.ORG

1. Promote choice making
2. Encourage exploration of possibilities
3. Promote reasonable risk taking
4. Encourage problem solving
5. Promote self-advocacy
6. Facilitate development of self-esteem
7. Develop goal setting and planning
8. Help youth understand their disabilities
2. JUDICIOUS USE OF AMPLIFICATION
Step 1. Potential Candidacy for HAT
Hearing Loss | Auditory Processing Deficit | Learning Disability
Auditory Neuropathy/Dys-synchrony
Language Deficit | Attention Deficit | English Language Learner

Step 2. Considerations
[in and out of school]
• Acoustic environment
• Social/emotional
• Functional
• Support

Step 3. Device Selection

Step 4. Fitting and Verification

Step 5. Implementation and Validation
Step 2. Considerations [in and out of school]
- Acoustic environment
- Social/emotional
  - Functional
  - Support

Contra-Indications?
- Motivation:
  - Student & teachers
  - Child & family
  - Attention & Fatigue
  - Self-image
- Self-advocacy
- Social acceptance
- Classroom culture
- Family support

Reconsider Counsel Monitor Review Yes
CONSIDERATIONS FOR SELECTION AND MANAGEMENT: HAT PLAN (IEP/504)

Device Determination:
Proceed with fitting, verification, & validation based on student preferences and assessment considerations.

Implementation:
When to use
Training for student
Training for teachers and staff

Management:
Monitoring device implementation & function

Goals:
Knowledge
Self-determination/Self-advocacy
Peer activities
TESTIMONIALS

Ethan: https://www.youtube.com/watch?v=TMv5UuSAsDs

Audrey (18):
https://drive.google.com/file/d/0B2y6mNHf9IWrR25jUnJ3Z0hvTlk/view

3. Peer Group Opportunities
4. Resources

PROFESSIONALS:
HTTPS://WWW.PHONAKPRO.COM/US/EN/RESOURCES/COUNSELING-TOOLS/PEDIATRIC/GUIDE-TO-ACCESS-PLANNING/GUIDE-TO-ACCESS-PLANNING.HTML

CONSUMERS:
Assess the patient’s communication strengths and weaknesses to take appropriate actions and reduce hearing loss.

Involve Communication Partners

Work with the patient to identify the most important people in their social network and to develop a shared strategy for communication.

Living Well with Hearing Loss

Bring the patient’s daily life and specific needs into the appointment as you identify communication situations that are relevant and important to them.

My World Pediatric Tool

Acquire the child’s perspective on their daily communication challenges and gain a unique insight into the child’s point of view.

GROUP AR Guide

Learn how to start a group rehabilitation program to help reduce return rates of hearing aids and to increase patient satisfaction.
Map It: What Comes Next

Review Information

Here is a snapshot of the Map It: What Comes Next self-determination training. This training is broken into three sections:

Section 1: Who Am I?
Section 2: What Do I Want?
Section 3: How Do I Get There?
TODAY IS MY TOMORROW. IT'S UP TO ME TO SHAPE IT, TO TAKE CONTROL AND SEIZE EVERY OPPORTUNITY. THE POWER IS IN THE CHOICES I MAKE EACH DAY. I EAT WELL, I LIVE WELL.

I SHAPE ME.