EFFECTIVE ADVOCACY & DISCLOSURE

A workshop for people on the autism spectrum

Westborough, MA

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PRESENTED BY
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AREAS OF ADVOCACY

Overview

What we are doing now to prepare for successful advocacy?

- Awareness of Need
  - Environmental
  - Cognitive
  - Social-Emotional

- Advocacy Effort

- Disclosure

INTERDEPENDENT LIVING FOR EDUCATION

Community

RELATIONSHIPS

Residential

EMPLOYMENT

INDIVIDUAL CONTRASTED WITH GROUP ADVOCACY

Overview

Making individual needs known in a way that others can understand and provide support

Making group needs known in a way that others can understand and provide support
ADVOCACY

Individual or Group?

She is autistic
She has autism

Identity First
Person First

Individual or Group?

The 4 A’s of Autism

What actions will you take to climb the stairs of Awareness, Acceptance, and Appreciation of people with differences in your lives?

ACTION
APPRECIATION
ACCEPTANCE
AWARENESS

What actions will you take to climb the stairs of Awareness, Acceptance, and Appreciation of people with differences in your lives?
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 it be from?

A LITTLE ABOUT ME
Introduction

The Autism Bomb — NOT

EXAMINING THE PARAMETERS
Questions to ask regarding possible areas of success

How does the s/he spend most of their time?

Reframe
• Communication
• Socialization
• Restricted Interests

Match to Ad/vocational Possibilities

Abilities?
Interests?
Kind of Mind?
Characteristics?
A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 4

AGE

0 1.5 2.5 4 6 8 10 13 19

EVENTS

Self Awareness

S U C C E S S W I T H A U T I S M

Set the Stage for Self-Determination

Condition improves to ‘neurotic’
The wonderful world of watch motors

Which Sets the Stage for Disclosure...

A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 6

Disclosure & Advocacy

4 6 8 10 13 19

Kindergarten

Social & academic difficulties

Discovered making a mess of myself while eating BBQ chicken wings

Loved cats but dogs...

Yikes bikes!
What about the Autism Spectrum (& other NDDs) makes it particularly challenging to disclose?

The issue of disclosure begins…

...As soon as it is known that a person has a difference in their way of being

WHY?
REALITY CHECK

Most people are busy with living
Most people are not in the mindset of accommodating people with differences

FOUR STEPS TO DISCLOSURE

1. Awareness of strengths and challenges through verbal, pictorial, and other communication.
2. "Rack up" strengths and challenges.
3. Non-judgmental comparison of characteristic with others and potential role models.
4. Present the label summarizing a condition rather than a name for a set of deficits.

Planning for Disclosure

1. Awareness of strengths and challenges
2. "Rack up" strengths and challenges
3. Nonjudgmental comparison
4. Present the label summarizing the condition

Making one's needs known in a way that others can understand and provide support.
A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 8

Disclosure – Telling another one is autistic

José is a good friend of yours and you always knew he was a bit different, yet you like him and accept him for who he is — quirks and all. As a stellar student, he aced his math tests, and as a trombonist in the band, memorizes his music after a quick glance.

However, in gym class, José is a complete flop. Even though he does well in bicycle racing and would probably excel in track, José performs poorly in baseball and other team sports. As a result, others have begun bullying José in the locker room, between classes, during recess, and after school.

Last week, José told you of his recent Asperger Syndrome diagnosis which explains his skills in math, music, and solitary sports and his challenges in team sports — perhaps due to difficulties in reading nonverbal communication and motor control.

You and José both now agree that disclosing the recent Asperger Syndrome diagnosis to the physical education teacher — whom you both trust — is necessary to stop the bullying.

Help José plan how to tell another he is autistic.

Help José prepare his disclosure of Asperger Syndrome to his physical education teacher using the 4 step disclosure process.

1. Strengths & Challenges
2. “Rack em up”
3. Nonjudgmental Comparison
4. Present the Label

Meaningful Disclosure

—Disclosing what autism means to Ted—

27 year old Ted has been asking why co-workers make fun of him during breaks, sees an occupational therapist weekly, takes an 10 full minutes address an envelope legibly, and to explain his general clumsiness at work. You notice that over the last month Ted’s questions have become more frequent.

Additionally, Ted no longer goes to the movies with you — his only friend — and has lost interest in train-spotting downtown, and generally seems listless.

Ted’s supervisor indicates he no longer helps his coworker Deb in mathematics in exchange for her assistance in drafting memos. Somehow, Deb has the ability to help Ted organize his thoughts for writing these messages to clients in a way no one else can.

As Ted’s friend, you decide to have a conversation with Ted to help him understand what having autism means to him.

Help Ted’s friend plan his discussion with Ted to help him understand what having autism means to him, emphasizing his characteristics while honoring strengths using the 4 step disclosure process.

1. Strengths & Challenges
2. “Rack em up”
3. Nonjudgmental Comparison
4. Present the Label
EFFECTIVE SELF-ADVOCACY

You’re Lost… And you ask someone for directions…

1. You suddenly realize there’s way too much information for you to remember
2. Hold on a moment! Can you wait a moment while I get something to take this down?
3. I won’t remember it all! Thanks for waiting...

WHAT & WHEN OF EFFECTIVE SELF-ADVOCACY

Self-advocacy involves knowing when and how to approach others in order to negotiate desired goals, and in order to build better mutual understanding, fulfillment, and productivity.

Successful self-advocacy often involves an amount of disclosure about oneself that carries some degree of risk, in order to reach a subsequent goal of better mutual understanding.

When the effect of being autistic or having another condition significantly impacts a situation or relationship and there is a need for better mutual understanding, it is time to build an advocacy plan.
LEARNING ADVOCACY THROUGH THE IEP

Engaging the Student

Who must we get on board?

- Student
  - Student’s Guide to the IEP
  - Helping Students Develop Their IEP
  - www.nichcy.org
- Parents
- Special Education Teacher
- Regular Education Teacher(s)
- Administrators
- Others

A Guide to the Individualized Education Program
Office of Special Education Programs. 16 June 2002.
<http://www.ed.gov/offices/OSERS/OSEP/Products/IEP_Guide/>

LeARNING ADVOCACY THROUGH THE IEP

Engaging the Student

MY STRENGTHS AND NEEDS

Note: This form is not required by IDEA

My Name: Date:

Class: 
Teacher: 

What do I do well?

What helps me do my best?

What do I need to do even better?

www.cec.sped.org

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Partial Table of Contents

LEARNING ADVOCACY THROUGH THE IEP

Engaging the Student

HELPING STUDENTS DEVELOP THEIR IEP

- Laying the Foundation
- Introductory Work with Students
- Introducing the IEP
- Writing the IEP
- Getting Ready for the IEP Meeting
- During the IEP Meeting
- After the Meeting

Student's Guide to the IEP

- What is an IEP?
- How do I develop my IEP?
- What to do before the IEP meeting
- Writing the IEP
- Getting ready for the IEP meeting
- Participating in the IEP meeting
- After the IEP meeting

SIX STAGES TO SELF-ADVOCACY

1. Planning and Modeling: After involvement with their own self-advocacy, the person observes the partner engage in the act of advocating.

2. Facilitation and Confidence Building: Facilitator serves as a guide for the self-advocacy process and remains ready to step in as needed.

3. Partnering and Letter Writing: Equal sharing of advocacy responsibilities. Advocate takes the lead as facilitator offers strong guidance, moral support while the person does most of the advocating. Letter writing.
**Six Stages to Self-Advocacy**

4. **Moral Support**: Partner continues to assist with the preparation. The advocate does most of the talking with the partner nearby to assist if needed.

5. **Taking the Lead**: The advocate leads the entire process with assistance from the facilitator but only under the self-advocate’s direction.

6. **Independent Self-Advocacy**: The advocate undertakes all the preparation, presentation, and evaluation in a completely independent manner.

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**Brenda the Hitter — Case Study**

— What do we do now… and teach her to advocate later —

While waiting in line ordered by height Brenda, who is in 8th grade, often hits other students and be accused of starting fights. Her usual response: “He or she bumped or hit me first!”

**FIRST**

1. Arrive at a possible explanation of this behavior, and,
2. what might be done about it in class?

**SECOND**

Choose one of the six stages of self-advocacy…
1. Planning and modeling
2. Facilitation and confidence building
3. Partnering and letter writing
4. Moral support
5. Taking the lead
6. Independent self-advocacy

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**Three-Step Process for Self-Advocacy**

1. **Build the foundation** — Awareness
   - Scan Sensory issues
   - Advocacy plan
   - Disclosure

2. **The reason why**
   - Inform another of one’s needs in a way they can provide support

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**A Closer Look at My Placement on the Autism Spectrum — 13**

- Middle and high school
- Finally getting it together but still often in left field
- Discovering the band room
- Time to focus more on people and not their bicycles

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**Interests, Relationships & Community**
What could have been done differently?

Was there successful advocacy here?

Individual or Group?
Helping Dot Advocate for Herself - Case Study

—Developing an Advocacy Plan—

Having just been moved from barely tolerable distraction of a shared office space to a cubicle of her own, 18-year old Dot is very proud of her new “digs.” However she quickly realizes the productive work will be impossible for her due to her fluorescent light sensitivity.

Her supervisor, while impressed with her work, does not know that Dot has Asperger Syndrome; and with it a sensitivity to fluorescent lights.

As Dot’s friend you realize that it is time for her develop an advocacy plan.

Please help Dot work through and develop a three-step advocacy plan.

1. SCAN — Find the challenge
   • Sensory
   • Cognitive
   • Socio-Emotional

2. ADVOCACY — Explain your needs
   • Mutual understanding/trust

3. DISCLOSURE — The reason why
   • Partial
   • Full

What is causing the difficulty?

• Sensory
• Cognitive
• Socio-emotional

The House of Self-Advocacy

Greater Self-Awareness
Better Mutual Understanding & Trust
Fulfilling and Productive Life

Disclosure
Full
Partial

Developing & Implementing an Advocacy Plan
Explain needs
• Clear communication
• Enable others to provide support

Scanning the Environment
What is causing the challenge?
• Sensory
• Cognitive
• Socio-emotional

SELF-AWARENESS
Disclosure – Telling another one has autism

—Help George plan how to tell another he has autism—

The best teller in the bank, George never uses a calculator and has cashed out to the penny for the past 15 months. He is also the first to help others having difficulties balancing their books, much to his coworkers’ gratitude – especially to Jane who is the bank’s star person to go to when there is a customer dispute. However George has dozens of notes stuck chaotically all over teller window and workspace. Conversations with his supervisor about an orderly workspace result in George indicating the necessity of these notes for remembering complicated bank procedures. Given his great efficiency and good nature, the branch supervisor leaves George to his work, albeit mystified.

A manager from corporate headquarters is coming next week. As a result, the supervisor has asked George to make an appointment with him to discuss the necessity of a clean, organized work space. Until now, George has never felt a need to disclose having autism to anyone. Given the recent turn of events, George now realizes perhaps this time has come.

Help George plan how to tell another he has autism

1. understand his needs using the 4 stages of self-disclosure, and,
2. The 3 step model for self-advocacy

Self-Disclosure Process
1. strengths & challenges,
2. “rack em up”,
3. nonjudgmental comparison,
4. present the label, and,
5. develop an advocacy plan

Self-Advocacy
1. Scanning
2. Advocacy
3. Disclosure
a. full or b. partial

SUCCESS WITH AUTISM
A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — ADULT

Sheltered Workshop for People with Asperger Syndrome

ADVOCACY IN COLLEGE
### Self-Initiated Individual Education Plan (Cont.)

**Accommodation Menu**

Note: This form is not required by IDEA

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<th>Student: Somebody</th>
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<tr>
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<td>IEP Manager: Everybody</td>
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<table>
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<th>Effectiveness (1-5)</th>
<th>Accommodation</th>
<th>Used?</th>
<th>Effectiveness (1-5)</th>
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<td>Small group</td>
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<td>Reduced paper/ pencil tasks</td>
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<td>Outline with due dates for assignments</td>
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<td>Small group</td>
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### Making College Right (Cont.)

**ACCOMMODATIONS WORKSHEET**

Name: Any Student  
School: Any State College  
Counselor: Unnamed Somebody  
Date: August 15, 2020

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Cause</th>
<th>Suggested Accommodation</th>
</tr>
</thead>
</table>
| Taking tests with multiple questions per page. | Visually over stimulating, gets lost in all the words | 1. Only one question per page.  
2. Two sheets of paper to cover distracting verbiage. |
| Unable to concentrate under fluorescent lights. | Perception of 60Hz cycling due to visual sensitivity | Explore alternate lighting, sit next to window, wear baseball cap in class. |
| Scheduling long term assignments. | Poor executive function. | Regularly meet with professor (perhaps once a week) to keep on target with lengthy assignments. |

### TURNING AWAY FROM CLOSED DOORS TO OPEN ONES

**Defining Success**