Enhancing Independence: A Collaborative and Dynamic Process

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Syosset Central School District

Parent Counseling

3/16/21

Education

Attended any postsecondary education
36%

Attended any college
30%

Employment

of the home

the home within the first two years

Living Arrangements

Lived independently
19%
Ever lived away from parents without supervision

Li

Ev

Social &

Any socialization
76%

service after high school

Any community participation
68%
Ever (in the past year) was involved in volunteer activities, community activities, or took classes or lessons

Received vocational services
37%
Ever received any vocational services or job training after high school

Co-occurring conditions
60%
of adolescents had two or more additional health or mental health conditions.

Bullying victimization
47%
of youth were victims of bullying during high school.

THE AVENUE
Only four out of ten working-age adults with disabilities are employed

Martha Ross and **Nicole Bateman** · Wednesday, July 25, 2018

Employment Status of Working Age Adults

With LD
Without LD

46%
71.3%

7.9% 6.4%

46%
22.3%

Employed   Unemployed   Not in Labor Force

Working Age Adults are considered ages 18-65. Source: H. Stephen Kaye, Unpublished tabulations of 2010 data from the U.S. Census Bureau Survey of Income and Program Participation

Starting with the "Why"

National Autism Indicators Report: Transition into Young Adulthood
Life Course Outcomes Research Program
A.J. Drexel Autism Institute, Drexel University
2015

How do we…

- ❖ Consider the skills needed to achieve independence;
   - ❖ Consider barriers to independence;
- ❖ Identify areas in need of support and improvement?

Self-Determination: Competence, autonomy, relatedness

Executive Function: Initiating, planning, shifting, executing tasks; inhibiting impulsivity

SKILLS NECESSARY TO ACHIEVING INDEPENDENCE

Functional Skills: Activities of daily living, vocational skills, community skills, functional academics

Communication: Receptive, expressive, pragmatic, functional communication

Executive Functioning skills

Impulse Control

Emotional Control

Self-Monitoring

Planning and Prioritizing

Working Memory

Flexible Thinking

Organization

Task Initiation

5 point scale	Explanation	What can I do?
5	I need help NOW!	Remove self from the situation—accept help from adults
4	I am really upset!	Count to 5 Take deep breaths Finger Touches
3	I've got a problem	Tell the teacher, ask for help, use break card, think positive thoughts
2	Things are pretty good!	Keep saying "I am going to be OK" to myself
1	I am feeling great!	Keep up the good work!

Supporting Executive Function

➔ Use of task analysis: breaking down instructions into steps
➔ Task analyses are also used as "visual schedules," to assist in time management, planning, and prioritizing
➔ Provide a clear expectation and consequence for any behavior: functional or vocational (clear the table, take out the garbage, time on computer)
➔ Color coding and other visual prompts: can be faded without adult interference
➔ Folders, task boxes: gives context for planning and expectations, allows the individual to self-pace and self-monitor
➔ "Self-regulation" chart: provides context for behavior
➔ Technology! Applications such as Google Keep, Egenda, First/Then Visual Schedule

Puts intervention in the individual's control as opposed to continued external prompts.

How do you, or can you implement this in your home?

Communication Skills

Expressive

Pragmatic

Receptive
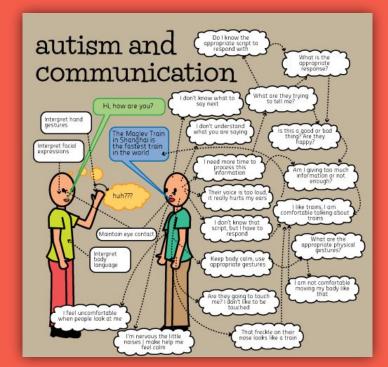
Supporting Communication

➔ Diagnoses (primarily ASD and speech/language impairment) impact receptive, expressive, and pragmatic (social) communication to varying degrees

➔ Evidence based practices to support acquisition include observational learning through video modeling, video self-modeling: encourages the individual to be an active participant

➔ **Peer-mediated interventions:** peer modeling and feedback

➔ Social stories, "priming" (modeled preparation for a situation) to frame upcoming or unknown situations, "social autopsy" to analyze a social interaction and make errors "teachable moments"

➔ **Functional communication training**: encouraging replacement language for challenging behavior, and reinforcing those phrases

How do you, or can you implement this in your home?

(Other) Functional Skills

➔ Functional routines for activities of daily living such as hygiene, self-care, medication management

➔ Community participation skills such as travel training, community navigation, safety awareness skills, shopping, leisure awareness

➔ Functional and applied academics: May include money recognition, writing a resume and cover letter, reading recipes; applying learned skills to life situations

➔ Pre-vocational skills: assessing and learning skills and programs that lead to employment

Many of these skills are being taught through classes and groups at the secondary level, and are also instructed through related services, supports, and programs

How do you, or can you implement this in your home?

Competence
The experience of mastery and being effective in one's activity

Autonomy
The feeling one has choice and willingly endorsing one's behavior

Relatedness
The need to feel connected and belongingness with others
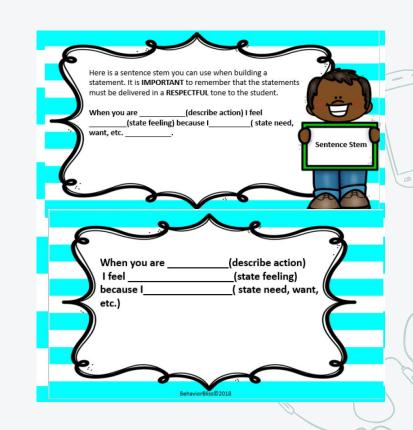
Motivation

Self-Determination

(Deci, E. & Ryan, R.)

Promoting Self-Determination

➔ "Know thyself!": encourage **self-advocacy,** communication of likes, dislikes, strengths and weaknesses
  ◆ Disclosure of classification and diagnoses can provide a sense of ownership
➔ Encourage the child to understand **what he/she needs and how to get it:** It's ok to ask for help!
➔ Wherever possible, provide choice: it encourages flexible and independent thinking
➔ **Set goals and priorities with the individual's input**
➔ Encourage self-determination through **interviews and surveys**
➔ Encourage **affective language**
➔ **SELF-MANAGEMENT:** Encouraging the individual to recognize their own behavior and provide the appropriate consequence. (such as self-reinforcement) For example, self-monitoring encourages internalizing external behavioral supports (ie, behavior charts, emotional regulation scales)

How do you, or can you implement this in your home?
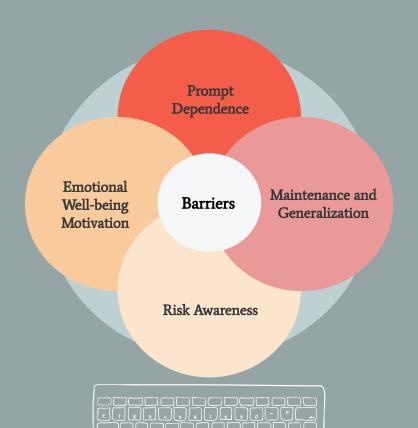
Affective Language: Restorative Practices

- ➔ May be "I" statements that express a feeling.
- ➔ Make individuals aware of either the positive or negative impact of their behavior.
- ➔ Provide a precise description of a behaviors and the specific impact of those behaviors.
- ➔ Are strategically delivered in a time frame, place and manner most likely to maximize impact.
- ➔ Focus on the behavior, NOT on the intrinsic worth of the person (separates the deed from doer).
- ➔ Are respectful in tone.
- ➔ Encourages individuals to express feelings.

Here is a sentence stem you can use when building a statement. It is IMPORTANT to remember that the statements must be delivered in a RESPECTFUL tone to the student.

When you are _____(describe action) I feel _____(state feeling) because I_____(state need, want, etc. _____.

Sentence Stem

When you are _____(describe action) I feel _____(state feeling) because I_____(state need, want, etc.)

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Barriers to Independence

Prompt Dependence

Emotional Well-being Motivation

Barriers

Maintenance and Generalization

Risk Awareness

Prompt Dependence

PROMPT HIERARCHY

least invasive → most invasive

more independent ← less independent

- **VISUAL** {includes positional}
- **VERBAL** {includes direct and indirect verbal prompts}
- **GESTURAL**
- **MODELING**
- **PARTIAL PHYSICAL**
- **FULL PHYSICAL**

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- ➜ Prompting is considered best practice to learn a new skill
- ➜ Prompting should start where the individual needs it, not more restrictive (for example, there is no need for a full physical prompt when a child responds correctly to a gesture prompt).
- ➜ However, individuals may become overly dependent on those prompts if we do not fade them systematically or within an appropriate amount of time
- ➜ This leads to learned helplessness

Consider how your child gets ready for school in the morning. What role do you have in that process?

Prompt + Fade = The Perfect Match

★ Fade to the natural cue in the environment.
★ Consider how you will fade the prompt before you decide to use it.
★ Be systematic.
★ Be flexible.
★ Monitor carefully.
★ Communicate level of fade to other people working on the same skill.
★ Probe. Occasionally take out the prompt to see how the individual is doing (getting another "baseline.")
★ Always individualize.

(Barbara Doyle, MS)

Maintenance and Generalization

➔ Generalization allows us to apply learned skills across settings, people, stimuli (materials) and responses

➔ Deficits in generalization make it difficult to apply this knowledge across varying situations

➔ Consider a situation where your child learned a specific chain of responses for eating dinner.
   ◆ Does that "chain" fall apart when you are not in the same setting? With the same people? Using the same utensils?

➔ Another example is social skills instruction in Speech, that does not generalize to the home or classroom

➔ Skills are maintained by continuing to practice them even after they are mastered. Otherwise, you risk losing competency in the skill, or lose the skill altogether.
   ◆ See: Marissa Zoffranieri's bike riding skills

Supporting generalization

"ANALOG"	"NATURALISTIC"
Highly structured work settings	Loosely structured work settings
Teach in "work" or a...	...ryday events
Trials initiated and...	... child
Take place in sa...	...settings
Stimulus always s...	...
Same stimuli	...
One acceptab...	...ponses
Same prompt, ie. "Do..."	Variety of prompts, "Show me," "Tell me,"
Rely on "artificial" reinforcers	Incorporate naturalistic, naturally occurring reinforcers

Everyone learns differently!
We generally use a combination of both teaching styles.

Risk Awareness

→ Consider the areas that may be impacted by diagnoses

→ Deficits in areas of communication impact functional language, relationship awareness, and boundaries ("stranger danger")

→ Deficits in areas of executive function impact problem solving, initiation, attention to task, and impulse control impact navigation of home and community

→ Deficits in functional skills impact safety in the community (reading signs, receiving correct change)

→ Consider situations which require you to react safely and quickly: for example, remembering to turn off the stove…

Risk Awareness

➔ Risk awareness **must** be specifically and explicitly taught.

➔ Instruction about how to navigate an emergency situation, and what constitutes an emergency and what does not (ie, "The TV isn't working!")

➔ Internalizing rules and responsibilities, "If…" "Then…"

➔ Teaching the difference between private and public; the right to privacy

➔ Training and education to identify the difference between strangers and trusted individuals in one's life…

HOW BIG IS MY PROBLEM?

5	EMERGENCY
	Earthquake, Fire, Danger to yourself or others
4	GIGANTIC PROBLEM
	Fighting, Someone is hurt, Destruction to the class
3	BIG PROBLEM
	Small accident (spilled something, fell down), Not feeling well, you are bleeding
2	MEDIUM PROBLEM
	Someone is bothering you, you need something,
1	LITTLE PROBLEM
	Runny nose, need to go to the bathroom, lost your supplies, having trouble on work
0	GLITCH
	Not getting called on, not getting the supply you wanted, losing in a game

Stranger Safety: Recent Research

Parents and clinicians will agree that safety with strangers is a highly valued and potentially life-saving skill that every person with disabilities should learn. This topic has been the focus of recent research and investigators have been careful to systematically replicate findings using a common standard for how people with disabilities should respond to strangers and a common set of stranger lures. These considerations across publishing researchers has been key to developing well-tested protocols for clinicians to use with clients.

The safety response used by recent research is a three-part response for which all aspects are scored as the dependent variable.

    Step 1: Tell the stranger "No."
    Step 2: Move away from the stranger
    Step 3: Report the incident right away

In addition, researchers have been careful to use similar abduction lures which are used in variation across teaching trials and generalization probes. The four abduction lures are as follows:

General/Simple: "Will you come with me?"
Authority: "Your mom told me to pick you up."
Incentive: "I have a soda for you if you come with me."
Assistance: "I lost my keys, will you help me find them?"

Finally, most participants in the recent research on stranger safety required some pre-requisite skills: a good vocal-verbal repertoire, demonstrated knowledge of the term stranger, ability to follow instructions, and ability to learn from modeling or role-play.

Fisher, M.H., Burke, M.M., & Griffin, M.M. (2013). Teaching young adults with disabilities to respond appropriately to lures from strangers. Journal of Applied Behavior Analysis, 46(2), 528- 533.

Social and Emotional Well-Being
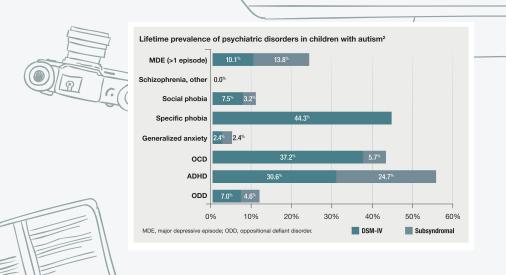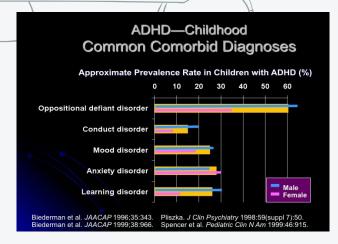
➔ Social-emotional well-being:
   ◆ Consider your own functioning.
   ◆ We all have our "off days:" Think about the effort that it takes to go through the entire day when you are not feeling well, feeling upset, or have experienced something traumatic
   ◆ Add the existing response effort required when a skill does not come naturally or easily to you
   ◆ Encourage self-regulation strategies such as meditation, progressive muscle relaxation, mindfulness
   ◆ Encourage positive and flexible thinking
   ◆ If necessary and appropriate, review medication management
➔ Considering Motivation:
   ◆ The individual must have a say, to "buy-in" to any intervention
   ◆ Lack of motivation and input in his/her own life can result in challenging behavior and frustration
   ◆ Self-determination is key, and naturally occurring consequences (positive and negative) should be addressed.
   ◆ Consider your own performance when you are not motivated (socially, financially, intrinsically)

Lifetime prevalence of psychiatric disorders in children with autism[2]

	DSM-IV	Subsyndromal
MDE (>1 episode)	10.1%	13.8%
Schizophrenia, other	0.0%	
Social phobia	7.5%	3.2%
Specific phobia	44.3%	
Generalized anxiety	2.4%	2.4%
OCD	37.2%	5.7%
ADHD	30.6%	24.7%
ODD	7.0%	4.6%

MDE, major depressive episode; ODD, oppositional defiant disorder.

ADHD—Childhood Common Comorbid Diagnoses

Approximate Prevalence Rate in Children with ADHD (%)

- Oppositional defiant disorder
- Conduct disorder
- Mood disorder
- Anxiety disorder
- Learning disorder

Male
Female

Biederman et al. *JAACAP* 1996;35:343.   Pliszka. *J Clin Psychiatry* 1998;59(suppl 7):50.
Biederman et al. *JAACAP* 1999;38:966.   Spencer et al. *Pediatric Clin N Am* 1999;46:915.

Emotional Well-Being

Heidi C. Collins, MD, Matthew S. Siegel, MD.

August 29, 2019. Special Reports, Autism,

Comorbidity In Psychiatry

*Comorbidity: occurrence of one diagnosis with another. For example, ADHD, ADD, Anxiety, OCD, and/or Depression may co-occur with autism spectrum disorder.

Final Thoughts

➔ All of these are linked, and impact all people differently.

➔ Independence is a lifelong process, and all people are capable of independence in some form.

➔ Having Realistic expectations does not mean lowering your expectations.

➔ Start small, and celebrate every step.

➔ Growth Mindset! Learn from mistakes.

➔ Use your resources, You are not alone!

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