

Autism in the Community: A Desensitization Approach

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About the Presenters

Anna Greenspan, OTR/L is the Occupational Therapy Supervisor at Monarch Center for Autism in Cleveland, Ohio. She has been employed at Monarch for more than 15 years, overseeing treatments and IEPs of more than 140 students, and collaborating with an interdisciplinary team of professionals. She was a guest lecturer at John Carroll University and presented on the topic of sensory support for the Cuyahoga Community College Occupational Therapy Assistant Program. She also guest lectured for The Autism Mini Series presented by Cleveland Clinic. Anna Greenspan also presented at Milestones Autism conference and Ohio Occupational Therapy conference on the topic of autism and community.

Kristy Yurichak, MOT, OTR/L received her Master of Occupational Therapy degree from Wayne State University in 2012. Currently, she is an occupational therapist at Monarch Center for Autism and specializes in organizing and implementing programs that improve independence within the areas of ADLs, fine/gross motor, visual perception, vocational, sensory processing and leisure. Additionally, she provides education and recommendations to school staff and parents regarding sensory strategies and environment modifications to help promote self-regulation. Ms. Yurichak is also a supervisor for level II occupational therapy graduate students. She has previously given poster presentations at the Michigan Occupational Therapy state conference and has presented at Ohio Occupational Therapy state conference and the OCALI conference.

Objectives

- Identify challenges for families with children who have Autism Spectrum Disorder (ASD) when participating in common community experiences
- Identify the child's sensory needs
- Explore ways to help the child desensitize to community experiences
- Teach caregivers how to assess the environment using a sensory approach
- Learn how to create and use visual language to aid with expectations
- Determine what supports should be placed within the community

Current Research

- Most recent CDC report identified 1 in 68 children (1 in 42 boys and 1 in 189 girls) as having autism spectrum disorder (2014).
- UCSF.edu states more than 90% of children with ASD also have atypical sensory behaviors and 5-16% percent of all children have sensory processing difficulties.
- Sensory experiences affect which occupations families chose to participate in and which to avoid, how the family prepared and the extent of shared meaningful experiences (Bagby, Dickie & Baranek, 2012).

Family Testimony

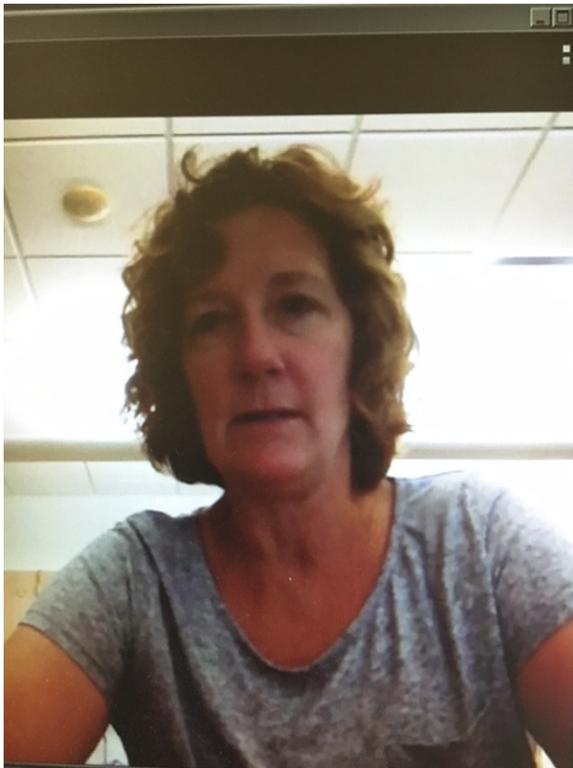


Jacob Myers, 20 years old

Has a brother with autism, who is 16 years old. His name is Josh.

- We had to do a lot of preplanning before we go into community
- We had to take a stroller with us because he would want to sit with blanket over his head because the lights and sounds in community were just a little too much for him
- Service dog made a difference in terms of transitioning
- We had to desensitize to foot measurement device and had to get a piece of paper to measure his foot
- The moral support we are giving him is important because when he sees us calm and okay it rubs off on him and helps him to be more active in community

Family Testimony



Kari Marx, Mother of young adult with autism

- Hardest part of taking someone with autism out into community is people not understanding what autism is and misjudging behaviors as bad parenthood
- Something that helped me was making trips short and rewarding him for good behaviors
- First Then schedules helped
- Making down time more structured

How Can We Improve Community Participation?

- Educating the community about autism
- Providing supports and education to the families of children with autism
- Encouraging and teaching the participation of families through a Desensitization Approach
- Using a **DESENSITIZATION APPROACH** that focuses on emphasizing the child's needs while building a positive foundation

Educating the Community about Autism

- <http://www.monarchcenterforautism.org/about-autism/autism-resources>
- Local resource (Northeast Ohio):
 - <http://www.livespecial.com>
- Resources suggested by individuals with autism:
 - <http://autisticadvocacy.org/>
 - <http://autismsciencefoundation.org/>
 - <http://www.autism.com/>
- Other resources:
 - <http://www.autism-society.org>
 - <http://www.autismspeaks.org>

The Desensitization Protocol

- Step guided protocol
- Purpose is to create a **POSITIVE** and **STRUCTURED** experience to improve community participation

Steps of Desensitization Protocol

1. **Build a Positive Relationship**
2. **Evaluate the child's sensory needs**
3. **Evaluate the child's executive skills**
4. **Assess the targeted environment**
5. **Create visual supports**
6. **Create community supports**
7. **Practice relevant experiences**

Step 1 Build a Positive Relationship

- The Three “R’s”
 - » *Respect*
 - » *Reinforce*
 - » *Relax*



Empathy

“Recognize their perspective is their truth...EMPATHY**”**



“Empathy fuels connection...”

<https://youtu.be/1Ewgu369Jw>

Respect

- Empathy



1. OT Brushing Video

Respect

- Respect your child and their sensory differences
 - » Know your child's likes and dislikes
 - » Provide a calming environment
 - » Provide the "just right challenge"
 - » Use a kind tone and positive words
 - » Remind them of the reinforcer
 - » Provide a safe environment



Respect

- Respect & understand your child and their sensory differences



Is your child ready to learn a new skill?

- a. Sitting with good posture
- b. Appears attentive and calm
- c. Connecting with the teacher
(i.e. appropriate responses)

Sensory regulation must be achieved before new learning takes place



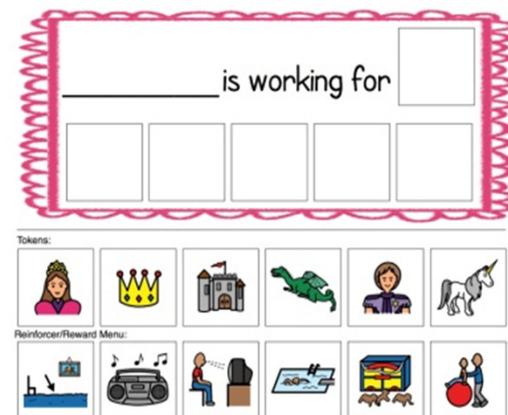
A Regulated Sensory System is the Root for All Other Developmental Skills



Image duplicated with permission from Asensorylife.com

Reinforce

- Positive reinforcement
- Know your child's preferred activity
- Preference assessment
- Ask parents or caregiver
- Token economies
- Have preferred objects in view or use visuals



Reinforcements are allowed to be changed. We all change our minds!

Relax

- Smile
- Don't raise voice
- Position self at eye level of your student
- Find the connection
- Be patient
- Be flexible, understanding, compassionate
- If needed, ask for help or support

Children can sense emotion quicker than adults

Your energy is transferable and detectable



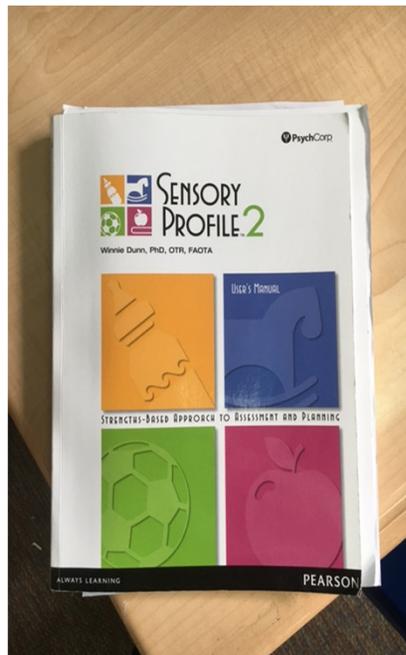
Step 2

Evaluate the Child's Sensory Needs

- Observations
- Parent/Teacher interview
- Child interview, if possible
- Checklists
- Sensory Profile



Evaluate the Child's Sensory Needs



	←Less Than Others		More Than				
	Others →						
	Quadrants						
	Raw Score Total	Percentile Range	Much Less Than Others	Less Than Others	Just Like The Majority Of Others	More Than Others	Much More Than Others
Seeking/Seeker	38/95	9-84	0----6	7----19	20--X-47	48---60	61---95
Avoiding/Avoider	40/100	8-86	0----7	8----20	21--X-46	47---59	60---100
Sensitivity/Sensor	28/95	9-86	0----6	7----17	18--X-42	43---53	54---95
Registration/Bystander	33/110	9-86	0----6	7----18	19--X-43	44--55	56--110
	Sensory Sections						
Auditory	16/40	12-85	0----2	3----9	10--X-24	25---31	32---40
Visual	8/30	3-10	0----4	5--X--8	9---17	18---21	22---30
Touch	11/55	11-87	0----0	1----7	8--X--21	22--28	29--55
Movement	8/40	8-85	0----1	2----6	7-X--18	19--24	25-40
Body Position	1/40	2-9	0----0	1X----4	5---15	16---19	20---40
Oral	16/50	8-87	**	0----7	8--X-24	25---32	30--50
	Behavioral Sections						
Conduct	12/45	6-84	0----1	2----8	9X--22	23---29	30---45
Social Emotional	34/70	86-96	0----2	3---12	13---31	32X--41	42---70
Attentional	32/50	94-99	0	1----8	9----24	25--31	32X-50

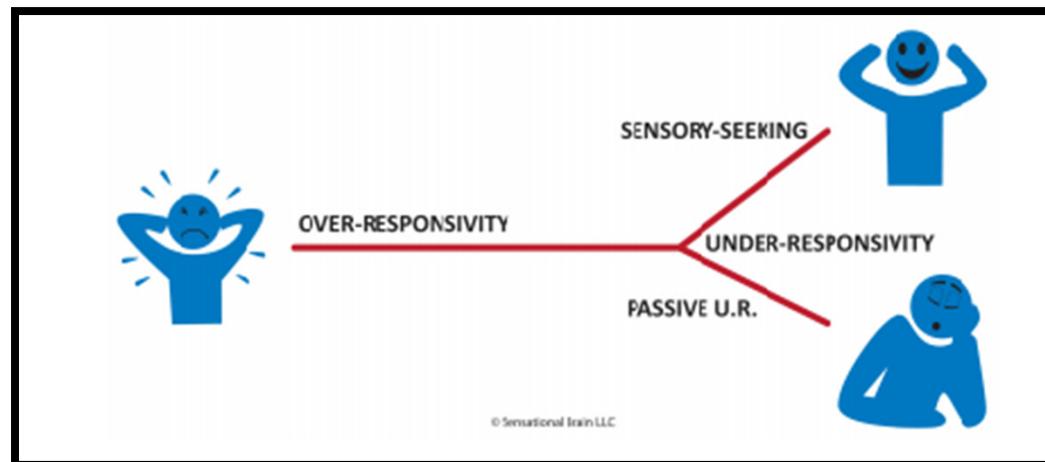
Observe: What do I look for?

Interview: What do I ask?

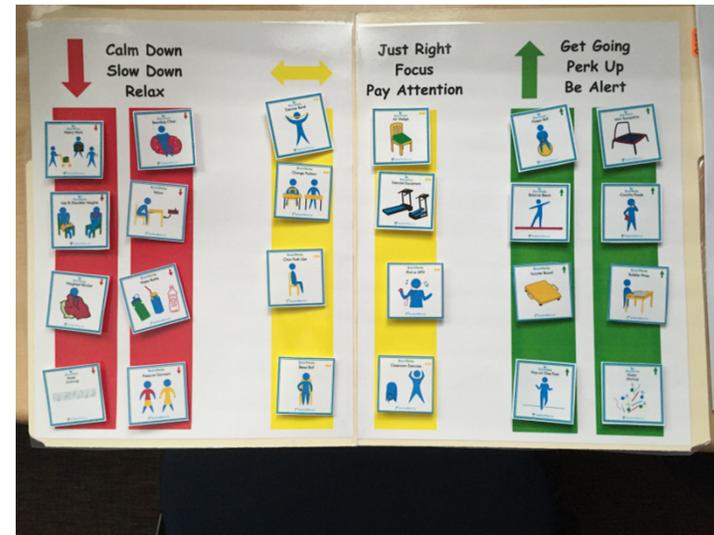
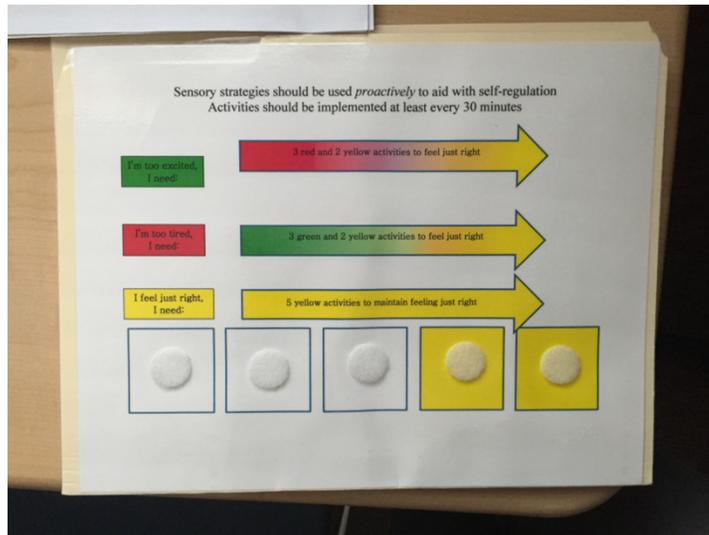
- Observe any physical or emotional responses to environmental stimuli
 - » Are the lights too bright?
 - ✓ child is closing eyes, head down, elopement, SIBS, PA
 - » Is the room too noisy?
 - ✓ child is covering ears, making own noise, elopement, SIBS, PA
 - » Are people distracting to the child?
 - ✓ child stops to look at others in room, unable to focus
 - » Is the child sitting still?
 - ✓ rocking, elopement
 - » Can the child tolerate touch? Smells?
 - ✓ avoiding touch, gagging

Sensory Checklists and Questionnaires

- Sensory Profile 2 Caregiver Questionnaire, Short Sensory Profile or Teacher Questionnaire
- Brainworks: Checklist that identifies over/under responsiveness, sensory seeking



Brainworks



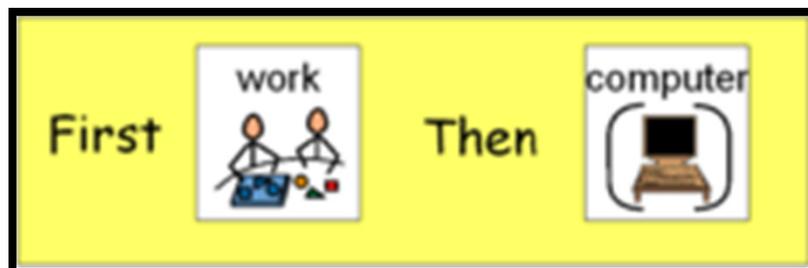
Sensory Checklists and Questionnaires

- Interpret the results
 - » Is the child over/under responsive/seeking?
 - » What are the child's specific sensitivities?
- Create child-specific sensory strategies and supports



Step 3 Evaluate the Child's Executive Skills

- Waiting
- Sitting
- Attending and following directions
- Understanding visual timer
- Understanding visual schedule
- Understanding First » Then



Step 4

Assess the Targeted Environment

- Use a sensory approach
- Identify environmental stimuli in relation to your child's sensory difficulties
 - » is the facility loud, crowded, unfamiliar?
 - » what type of equipment is used?



Activity Analysis

- Identify the experience (doctor, salon, restaurant, dentist, etc.)
- Break down the experience into components
 - a. Identify the space
 - b. Identify social demands
 - c. Identify objects

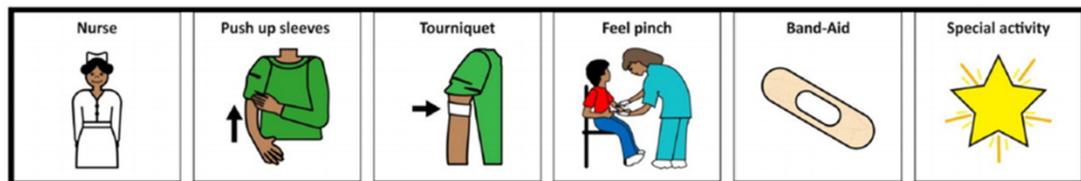


Step 5 Create Visual Supports

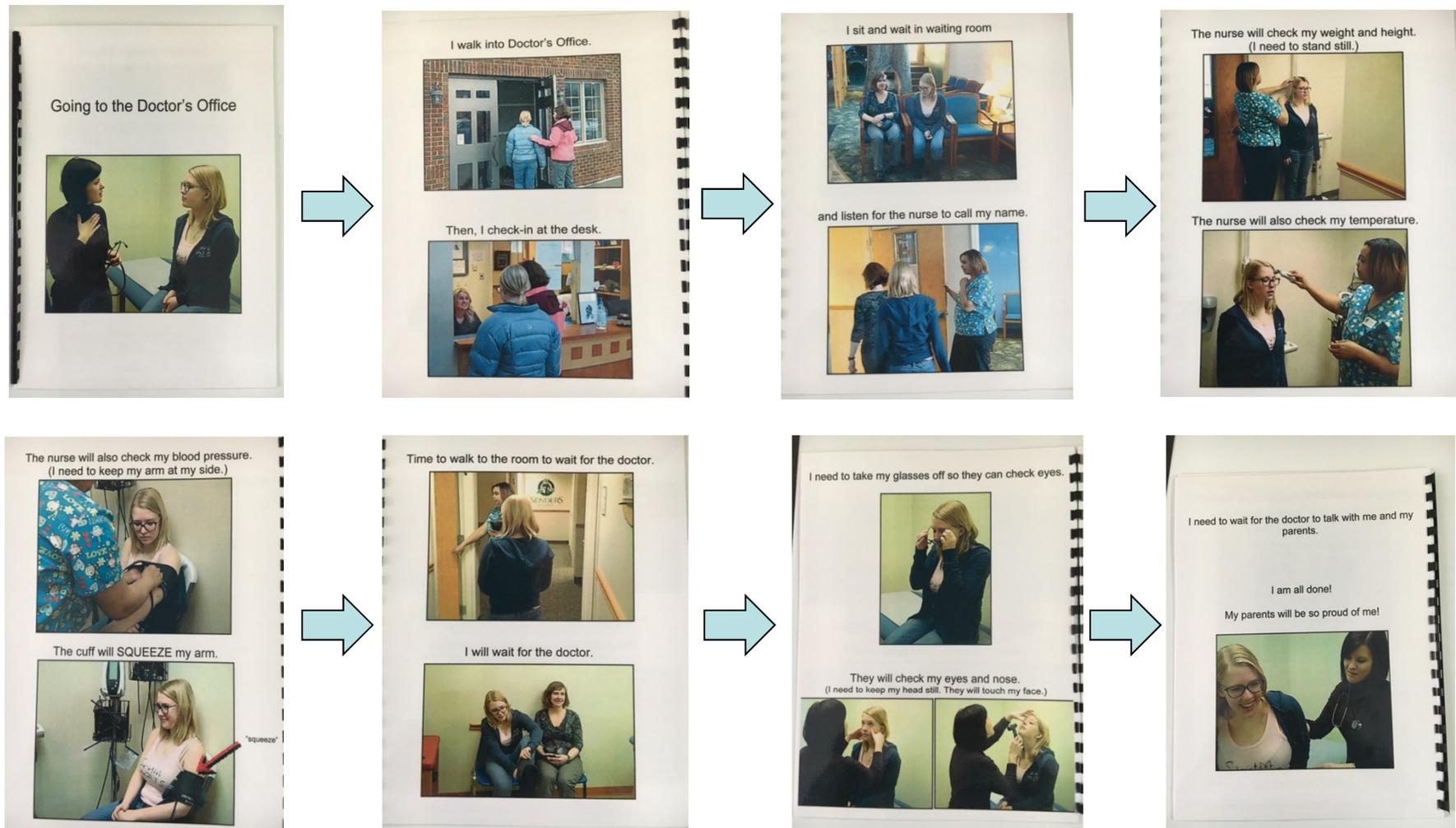
- Limit verbalizations and utilize visual strategies
- Visual language comprehension
 - » First-Then Board
 - » Visual Schedules
 - » Visual Timers
 - » Social Stories
 - » Video Models



Getting a Shot:



Example of a Social Story



Step 6

Create community supports

- Educate
- Advocate
- Community bags
- Physician-Patient questionnaire



Patient – Doctor, Information to Consider

- When is it best to schedule the appointment?
Morning
Afternoon
Evening

- Can your child wait in the waiting room?
Yes
No

- What makes your child frustrated/anxious?

- What supports are necessary for your child to be calm?

- How does your child communicate his/her needs? (e.g. communication device, IPAD, PECS)

Patient – Doctor, Information to Consider

- Sensitivity to the sight or sound ?
- Is your child bothered by fluorescent lighting?
- Does your child ever eats or tastes things that are not food (e.g. Purrell, lotion, soap)?
- Is your child sensitive to the touch of creams, gels or wipes to his/her skin?
- Is your child able to stay seated (30 seconds, 1 minute, 5 minutes)?
Do they respond better when standing up?
- If asked a yes/no question about what they see or feel (e.g. “Can you see my light?” or “Does this hurt when I touch here?”), is your child likely to answer correctly?
- Is your child able to make a choice (verbally, through text, device, gesture or action)?
(e.g. “Do you want to sit in this chair or on this table?”)

My Community Bag: What to bring

- Dry/erase board marker
- Visual timer
- Wait card
- Headphones
- Schedule/Social Story
- First/Then board
- Token board
- iPad



'I Have Autism' Card

Hello,
My name is _____.

I have autism. Sometimes autism is called an "invisible diagnosis" because you can't see it in my face or in my body. But I feel different from others.

Crowded spaces may make me feel pain in my skin.

Loud noises may make me feel pain in my ears.

Bright lights may make me feel pain in my eyes.

I get anxious when my routines are changed and I don't know what is coming next.

Too many words may make me feel confused.

I am trying to learn, but right now I am having a difficult time.

I am sorry if I am loud and disruptive.

My family and I are aware that my behaviors might bring unwanted attention. Please accept me and don't judge me.

I want to learn, I just need some time.

Thank you for understanding.

If you would like to learn more about autism, please go to:
www.autism-society.org

Step 7

Practice Relevant Experiences

- First practice in a safe, familiar environment
 - » Use real objects
- Use play
- The “just right challenge”
- Start with little steps within the environment
 - » First drive by the space
 - » Park in parking lot
 - » Walk into the building



Practice Relevant Experiences



2. Blood Pressure Video



3. Nail Clip Video

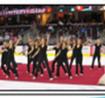


4. Nail Clip on Bear Video

Be Consistent

- Teach routines and visual language concepts
- Have visual supports to ensure your child understands what is expected of him/her
- Be predictable but have the goal of making small changes

Lake Erie Monsters Hockey Game
Visual Schedule

Event	Where	Who	What	How Long	Reward
<p>Lake Erie Monsters Hockey Game</p> 	<p>Quicken Loans Arena</p> 	<p>Me</p>  <p>Mom</p>  <p>Dad</p>  <p>Sister</p> 	<p>Drive to game</p>  <p>Wait in line</p>  <p>Find seats</p>  <p>Watch game</p>  <p>Take a break</p>  <p>Watch game</p>  <p>Drive home</p> 	<p>2.5 hours</p>  <p>60 minutes</p>  <p>60 minutes</p>  <p>30 minutes</p> 	<p>Eat a snack</p>  <p>Play a game</p>  <p>See mascot</p>  <p>Watch dancers</p> 

Family Testimony, Success Story



Leslie Myers, Mother of youth with autism

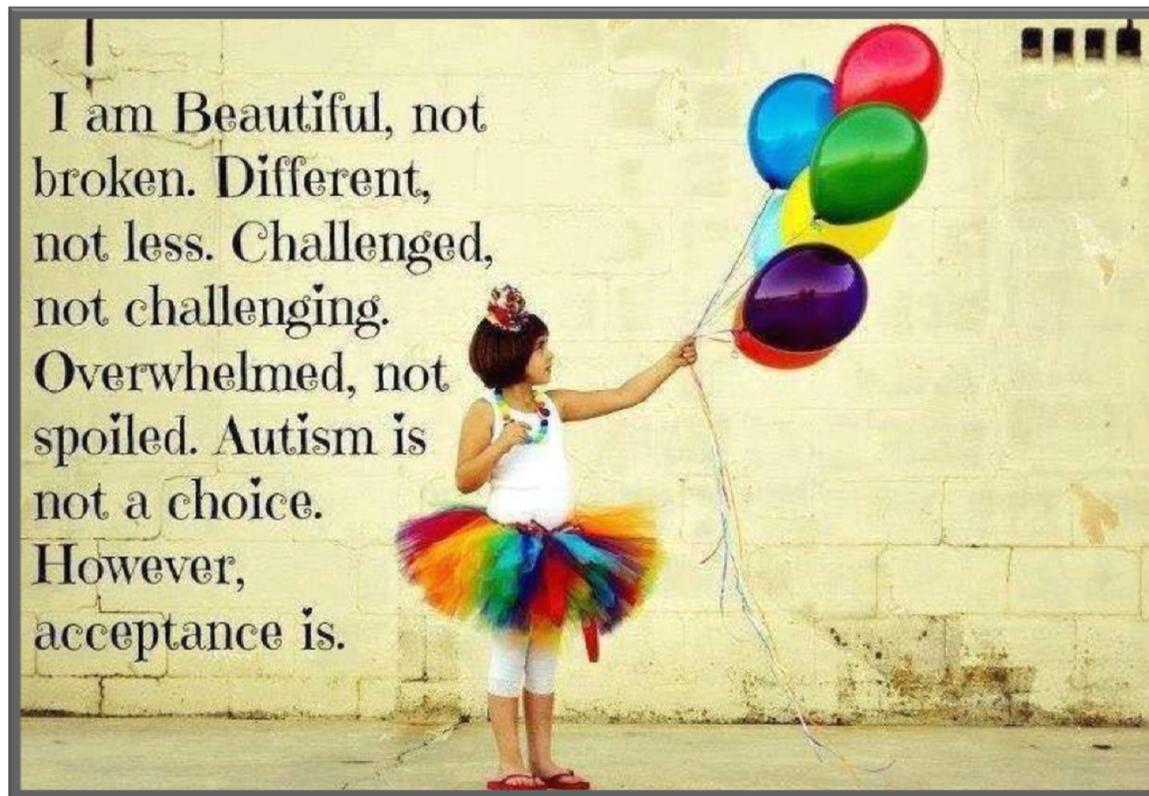
- Josh is 16 years old
- Had SI issues
- As toddler he walked on tiptoes and flapped his hands
- He walked in circles around objects and did lots of twirling
- Covered his ears with his hands, liked blanket over his head
- Could not tolerate solid food till about 4 years
- Today's issues are more community based
- He has difficulties going to doctor, going to dentist, buying shoes
- Haircuts used to take 3 ½ hours

Family Testimony, Success Story Continues



With Desensitization Program

- Haircuts are now 20 minutes
- Josh tolerates stethoscope
- Shoe sizer
- Blood pressure cuff
- Eye exam
- At last Dr. appointment Josh was able to get weight/height
- Nurse was able to shine light in his mouth
- Nurse was able to wear gloves during the exam
- Josh was able to tolerate BP cuff on with 2-3 puffs of air in it
- Desensitization worked better than I expected. I am so grateful!



References

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Questions / Comments



Monarch Center for Autism Services

- ❖ **Preschool**
- ❖ **Day School**
- ❖ **Transition Education Program**
- ❖ **Extended School Year Program**
- ❖ **Summer Social Language Leadership Program**
- ❖ **Boarding Academy**
- ❖ **Adult Autism Program**
- ❖ **Adult Autism Residence & Support Living Settings**
- ❖ **Free Webinar & e-newsletter Series**
- ❖ **Online Resource Center**

- ✦ **Web:** www.monarchcenterforautism.org
- ✦ **Telephone:** 216.320.8945 or 1-800-879-2522
- ✦ **Address:** 22001 Fairmount Boulevard,
Shaker Heights, Ohio 44118
- ✦ **Join our e-newsletter mailing list:**
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