Autism Spectrum Disorder Part II: Medical Home Care for Children with ASD and Other Developmental Disabilities

Robin K Blitz, MD, FAAP
Senior Medical Director, Special Needs Initiative
UnitedHealthcare

Learning Objectives

At the end of this educational activity, participants should be able to:

- Describe medical home care for children with ASD.
- Implement counseling strategies for parents, caregivers and family members on effective ASD management strategies.
- Identify community resources available for families.
- Describe autism-sensitive care in the office, emergency department and hospital.
Medical Home Care

Medical Home Care for the Child with Autism Spectrum Disorder

• 2009-2010 National Survey of CYSHCN:
  – Prevalence = 13.9%
  – Less than 50% had access to a medical home
• Children with ASD – least access to a medical home
• PCPs report:
  – Overall lower competency,
  – Greater need for primary care improvement, and;
  – Greater desire for education regarding ASD.
• Family-centered care
A medical home is not a building or place

7 Key Components:

- Access to care
- Family-centered care
- Cultural responsiveness
- Continuity of care
- Comprehensive care
- Compassionate care
- Coordination of care

With the help of a medical home approach, PCP and Parent are able to coordinate all aspects of care – eliminating the difficulties of navigation and fragmented care

Medical Home Care
Assorted Medical Conditions

Care of a child with ASD is 24 / 7 / 52

- GI: 9-70% – chronic constipation / diarrhea, recurrent abdominal pain, celiac, GER, eating and feeding challenges
- Seizures: 20-33%
- Sleep problems: up to 86%
- Common childhood illnesses: Ear infections, headaches, allergies, asthma, dental
- Not so common: Diabetes, juvenile rheumatoid arthritis (JRA), leukemia
- Behavioral Health: ADHD, anxiety, depression
Medical Home Care
Nutrition / Feeding problems

- Emily only ate Lorna Doone cookies and milk
- Jimmy’s mom was a genius
- Underweight and / or nutrient deficiencies: iron, vitamin D, protein
- Pica
- Casein-free and gluten-free diet

What About Sleep?

- Sleep problems may include:
  - Sleep onset delay
  - Frequent and prolonged night wakening
  - Early rising
  - Less sleep overall
- Monitor for obstructive sleep apnea (OSA), restless legs, seizures and anxiety
- Results in daytime learning, attention & behavior problems
- Studies find genetic mutations, less REM sleep
- Parents have chronic stress
Children with ASD May Have Sensory Processing Problems

- High pain tolerance or unusual response
- Tactile hypersensitivity
  - Become upset if touched
  - Band-Aids, other adhesives
  - Examine slowly
- Expect the unexpected
  - Ingestions
- Wrap in blanket with arms inside

Medical Home Care Challenging Behaviors

- Aggression – hitting, biting, pinching
- Disruptive – screaming, tantrums
- Self-injurious – head-banging, self-punching, slamming into desks
- Self-stimulatory – rocking, masturbating, self-spinning
Questions to Consider

- Significance of behavior?
- Pain, upset, or self-soothing?
- Level of cognitive, verbal, social interaction abilities?
- Best way to communicate / interact with this child?
- What calms and soothes the child?
  - What has the opposite effect?
- How to facilitate the medical care of the child?

The Case of Ryan

Meet Ryan

- 5 years old, nonverbal, autism
- New onset self-injurious behavior – slamming into tables, desks
- No other changes in family, school, social life
- No signs or symptoms of illness
- Independent in dressing, toileting, eating
The Case of David

Meet David

- Mild to moderate autism, verbal
- He presents with a 2-month history of unexplained aggressive outbursts
- He could not explain the outbursts of rage
- Examination is unremarkable

The Case of Eduardo

Meet Eduardo

- 15 years old, severe autism, non-verbal
- On Risperdal® (risperidone) per psychiatrist
- New onset self-injurious behavior – punching his left cheek repeatedly
- No changes in family, school, social life
- Bruising and swelling of his left cheek
The Case of Joey

Meet Joey

- Moderate to severe autism
- Presents to the ED with sudden onset self-injurious behavior (SIB) and destructive behavior
- Various neuroleptics for increasing agitation and sleep problems, with no success over the past year
- Multiple respiratory infections
- Frequently coughs and this keeps him up at night

What to do if the Child is Carrying Out Undesired Behaviors?

- Investigate reason for behavior
- Give no reaction, praise, or reinforcement when a request is refused or when an inappropriate behavior is exhibited (REALLY HARD!)
- Instead of stating “No,” “Stop,” or “Don’t” direct the child to what you want them to do
  - Then reward when the action is carried out
- Minimize the use of restraints

Souders et al., 2003
The Needs of the Child with ASD in the Hospital / ED / Office

- Increased anxiety and distress due to novel sounds, smells, visual stimuli and tactile experiences
- Pragmatic assessment of the communication strategies and sensory differences unique to each individual is essential in the development of an appropriate inpatient care plan
- Consult with the Expert – THE PARENT


Expressive Communication

Modes of communication are variant, but all express needs or desires

- 38% Sign
- 31% AAC
- 23% Verbal
- 8% Other

Receptive Communication

Modes of receiving new information are variant, but all support understanding

- Written language: 57%
- AAC: 23%
- Verbal: 11%
- Other: 9%


Expression of Pain

Being able to recognize pain indicators is critical to care and security

- Cry / Scream: 32%
- SIB / Aggression: 19%
- Verbal: 15%
- Pointing: 7%
- Other: 27%

Best Way to Examine a Child with ASD

It is easier to examine a child who is calm, than one who is distressed

- Explain verbally: 50%
- Model / allow pts to examine instruments: 37%
- Distract: 6%
- Other: 7%


Understand Passage of Time

Helping the child understand passage of time can help decrease stress and anxiety

- Schedule Board: 30%
- Clock: 17%
- Timer: 17%
- Counting aloud: 8%
- Did not understand: 8%
- Other: 20%

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In the Office
What to Do / Suggestions for Care

• Decrease environmental stimuli: light, noise, chaos
• Use Visual Communication Systems
• Provide as much consistency as possible
• Have family members present as much as possible
• Transition planning / designated breaks
• Behavioral techniques
  • Avoid things that are known to agitate
  • Offer choices
• OT Supports – Sensory Integration

In the Office
What to Do / Suggestions for Care

• Consult with the Expert – THE PARENT
• Develop ASD-sensitive care
• Understand that the most common problem when a child is sick is increased anxiety, sensory processing and communication
• Understand the spectrum of ASD
Parents Know Best!

- **Family-centered care**
  - Collaborate with family members to develop optimal plan of care for the child
- **Strategies to prevent challenging behaviors of the hospitalized child** may lead to:
  - Improved safety
  - Decreased cost of care
  - A more satisfactory experience for parents, child, and staff

Scarpinato, et al. 2010

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Parents Know Best!

Health care professionals (HCPs) should consider asking:

- How does your child tolerate new faces?
- How does he/she react to other children? To adults?
- Is he/she sensitive to anything?
- What is the best way to approach him/her?
- How does he/she communicate?
- How does he/she report or express pain?
Parents Know Best!

HCPs should consider asking:

– Are there any items of fixation for your child? If so, how does the family manage these?
– What are some things that agitate him/her?
– What early warning signs may indicate that he/she is agitated?
– When he/she becomes agitated or overstimulated, what interventions work best?

Parents Know Best!

HCPs should consider asking:

– What is this child’s schedule at home?
– How much can the hospital’s routine mirror his/her home schedule?
– How can I best prepare him/her for upcoming transitions?
– What is his/her developmental level?
Complementary and Alternative Medicine

Medical Home Care
Fielding Tough Questions

- Alternative therapies and interventions
  - Very little to no evidence of benefit
  - 95% of parents use some type of CAM therapy
  - Levy and Hyman, Child Adol Psychiatr Clin N Am. 2008 October
## Medical Home Care - CAM

http://nccam.nih.gov/

<table>
<thead>
<tr>
<th>Diet / Supplements</th>
<th>Biological Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>– Gluten- and/or casein-free diets</td>
<td>– Antifungal</td>
</tr>
<tr>
<td>– Essential fatty acids</td>
<td>– Melatonin</td>
</tr>
<tr>
<td>– Probiotics</td>
<td>– Homeopathy</td>
</tr>
<tr>
<td>– Digestive enzymes</td>
<td>– Antibiotics</td>
</tr>
<tr>
<td>– Carnitine</td>
<td>– Secretin</td>
</tr>
</tbody>
</table>

**Other CAM Therapy**

| | |
| – Sensory integration | – Chelation |
| – Chiropractor | |
| – Vaccination delay, separation, or refusal | |

| Other CAM Therapy | |
| – Sensory integration | |
| – Chiropractor | |
| – Vaccination delay, separation, or refusal | |

## Medical Home Care

**Fielding Tough Questions**

- The role of immunizations, thimerosal
  - No evidence of an association
  - [https://healthychildren.org/English/safety-prevention/immunizations/Pages/Vaccine-Safety-The-Facts.aspx](https://healthychildren.org/English/safety-prevention/immunizations/Pages/Vaccine-Safety-The-Facts.aspx)
<table>
<thead>
<tr>
<th>FINDING</th>
<th>MERCURY POISONING</th>
<th>AUTISM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor</td>
<td>Ataxia</td>
<td>Repetitive behavior</td>
</tr>
<tr>
<td>Vision</td>
<td>Bilat. visual field constrict</td>
<td>No problems</td>
</tr>
<tr>
<td>Speech</td>
<td>Dysarthria</td>
<td>Delayed speech, echolalia</td>
</tr>
<tr>
<td>Sensory</td>
<td>Peripheral neuropathy, paresthesias</td>
<td>Decreased pain response, hyperacusis, hypersensitive to sensory stimuli</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Toxic psychosis; mild nonspecific depression, anx, irritability</td>
<td>Socially aloof, insistence on sameness</td>
</tr>
<tr>
<td>Head size</td>
<td>Small</td>
<td>Large</td>
</tr>
<tr>
<td>Other</td>
<td>Chronic mercury toxicity: HTN, skin eruption, thrombocytopenia</td>
<td>Seldom seen</td>
</tr>
</tbody>
</table>
Medical Home Care
Investigate Resources in Your Community

• Early Intervention
• School Services
• State Services
• Parent Support Services / Respite
• Community Organizations
• What therapies are available and from where?

Autism Treatment
Early Intervention and School

• Early Intervention
• School District / Individual Education Plan (IEP)
  – 3-5 yo: Special Needs Preschool
  – 5-22 yo: Elementary, Middle, High School
• Individual Transition Plan
  – 18-22 yo
  – Start planning at 14 or 16 yo
Other Treatment

Autism Treatment
Behavioral Interventions

- Applied Behavioral Analysis
- Floor time Relationship Development Intervention (RDI)
- Eclectic models
  - Early Start Denver Model
  - Project Impact
- See ASD Part IV – September 11, 2018
Autism Treatment
Medical Interventions

• Sleep – restless, insomnia, OSA
• GI – selective eating, nutrition, constipation
• Seizures – use anticonvulsants with mood stabilizing qualities
• Psych – anxiety, ADHD, irritability, aggression

https://www.autismspeaks.org/family-services/tool-kits

Autism Speaks Resources

ATN/AIR-P Guides to Pica for Parents and Professionals

Pica, the repeated eating of non-food items, is the eating disorder most often displayed by children with autism. In published literature, the most common definition of pica is the placing of non-edible items past the plane of the lips. For example, a child would... More

ATN/AIR-P Medication Decision Aid

Many families of children with autism spectrum disorder (ASD) are faced with the option of using medicines to help treat their child’s challenging behaviors. This is a tough medical decision and there is no one right answer. Though many children... More

ATN/AIR-P Melatonin and Sleep Problems: A Guide for Parents

Melatonin is a hormone that helps regulate sleep and wake cycles. Many children with ASD have trouble sleeping and melatonin can help... More
What Else Can We Do?

- Picture schedules
- Social Stories Priming
- Story boards
- First-then boards
- Video-modeling
- Practice with toy doctor’s equipment
- Reward Charts

Social Stories / Picture Schedules / Medical Priming

Use of pictures or a verbal story can:
- Help prepare the child for an upcoming event
- Help the child understand what an appropriate response to a situation may be
Preparing for Procedures

Look at Me Now! LLC

- Pay a small fee for access to:
  - First-then boards
  - Story boards
  - Social story priming
  - Video-modeling

Search: Look at Me Now Autism Videos

Consider having your child watch a sibling go through similar experiences

Preparing for Procedures

Autism Speaks Family Toolkits

https://www.autismspeaks.org/family-services/tool-kits
ATN/AIR-P Blood Draw Tool Kit

Blood Draw Tool Kit for Parents

Has your child with ASD had a negative experience during a doctor’s visit that has left him or her feeling anxious? Does the prospect of having your child’s blood drawn make you nervous as well? Perhaps this anxiety has even prevented you from seeking needed tests and treatments. This toolkit was designed with you and your child in mind. It provides a variety of tools to help you and your child to prepare for future medical visits and reduce the stress and worry that may come with blood draws. Inside, you will find strategies easing your child’s medical appointments, particularly those involving blood work. The kit’s resources include ready-made visual supports, social stories, relaxation and distraction techniques, and tips designed specifically for children with ASD. Although “Taking the Work Out of Blood Work” focuses on phlebotomy, the information and techniques presented here also apply to other aspects of a clinic visit, such as measuring vital signs, undergoing physical exams and tolerating those inevitable wait times. A medical provider version of this toolkit is also available. Send a

Resources – Visual Supports

Visual Supports and Autism Spectrum Disorders

Introduction

What are visual supports? Visual supports are pictures or diagrams used to help facilitate communication with a child with autism, enabling them to communicate their thoughts, needs, and preferences. Visual supports can be used in various settings, including schools, homes, and public places. They help to improve communication skills, reduce anxiety, and enhance social interactions.

Visual supports are used with children with autism spectrum disorders (ASDs) for better communication. They help parents, teachers, and caregivers to better understand the child’s needs and preferences. Visual supports can be used to support a wide range of activities, from daily routines to social interactions.

Visual supports are used in schools to support children with ASDs in understanding the curriculum and achieving academic success. They are also used in hospitals to help children understand medical procedures and treatments.

Using visual supports effectively involves creating a diverse range of visual representations, including pictures, symbols, and written text. It is important to use a variety of visual supports to cater to different communication styles and preferences.

Conclusion

Visual supports are an essential tool for individuals on the autism spectrum. They help to improve communication, reduce anxiety, and enhance social interactions. By using visual supports effectively, we can help individuals with ASDs to achieve their full potential.
Resources – First Then Boards

What Is A First-Then Board?
A First-Then board is a visual display that motivates patients to engage in medical procedures that are not preferred by clarifying the preferred items/activities that will be available after it is over.

First-Then Board

<table>
<thead>
<tr>
<th>FIRST</th>
<th>THEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel pinch</td>
<td>Play with cars</td>
</tr>
<tr>
<td>Doctor visit</td>
<td>Playground</td>
</tr>
</tbody>
</table>

Visual Supports for Phlebotomy

Visual Supports for Phlebotomy

Walk | Run | Fall
Chair | Sit down | Listen
Push up sleeves | Wipe off arm | Cold
Tourniquet | Cold spray | Ice pack
Visual Supports for Phlebotomy

Resources – Autism Speaks

Visual Phlebotomy Toolkit for Providers Treating Children with Autism

- Squish ball
- Feed chair
- Cotton balls
- Cotton ball on arm
- Bandage
- All done
- Happy
- Doctor visit
- Keep arms at sides
- Blood pressure
- Please wait
- Doctor visit
- Laugh
- Pinwheel
- Change channel
- Take deep breath
- Belly breathing
- Stretch
- Think
- Blow
- Blow bubbles

Resources for Daily Living

Deep breathing instructions for children with ASD:

1. Get comfortable. Sit on the floor or sit up straight.
2. Put one hand on your chest and the other hand over your belly.
3. Squeeze through your nose (1,2,3,4) when you breathe in, feel your belly rise like a balloon.
4. Stretch out, holding your hand on your belly.
5. Breathe out, feeling your belly go back in, like a balloon deflating.
6. Keep breathing like this a few more times.

The more you practice, the easier it will become!

Using the child’s visual — like a picture to pair with belly breathing. Taking the child’s picture of blowing and/or blowing a pinwheel — will help make practicing deep breathing more enjoyable and easier to follow. You can also provide a distraction using a visual during a calming intervention.

Note: If the child with ASD still has consciousness during paroxysmal events, check with a physician before using deep breathing or muscle relaxation.

Blowing Bubbles

This technique is simple and soothing. Have the child get comfortable (for example, lean back in a chair) and blow bubbles (small) for a few seconds. Then, have the child blow bubbles (large) for a few seconds. This helps the child focus on watching the bubble fall and repeat the process.

Pinwheel

Encourage the child to take a deep breath and blow out deeply in the pinwheel. See how long the child can make the pinwheel move. The longer he or she can, the longer the pinwheel will spin.

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Resources – Autism Speaks

APPENDIX C: MUSCLE-RELAXING TRAINING SCRIPT

When you feel tense, upset, or concerned, muscles in your body often tighten. By practicing tension-release exercises, you will learn to relax them. These two exercises include muscle relaxation and stretching exercises. You can use them to reduce muscle tension and stress.

1.ひとえをこする

Sit in a chair or on the floor. Cross your legs and place your hands on your knees. Slowly pull your arms up and over your head, keeping your shoulders relaxed. Hold for 10 seconds. Repeat 3 times.

2.肩をすくめる

Stand up straight and bring your shoulders forward. Slowly lower your shoulders down, keeping them relaxed. Hold for 10 seconds. Repeat 3 times.

3.腕を伸ばす

Reach your arms up over your head, pressing your palms together. Hold for 10 seconds. Repeat 3 times.

4.首を伸ばす

Slowly move your neck from side to side, keeping your shoulders relaxed. Hold for 10 seconds. Repeat 3 times.

Summary
People First Language
Essential for Family-Centered Care

A disability descriptor is simply a medical diagnosis. People First Language respectfully puts the person before the disability.

A person with a disability is more like people without disabilities than different!

- NOT the Downs Kid – The child with Down syndrome
- NOT the Autistic Kid – The child with Autism
- NOT the Retarded Kid – The child with an intellectual disability

In Summary
Best Practice Recommendations

- Provide Medical Home / Family-centered Care
- Use People First Language
- Collaboration of providers and staff with family members and their caregivers is crucial
- Empower the parent

Listen to parents’ concerns.
Remember – Parents are the Experts!
## Resources and References

### Autism

- Autism Society of America
  - [www.autism-society.org](http://www.autism-society.org)
- Autism Speaks
  - [www.autismspeaks.org](http://www.autismspeaks.org)
  - [https://www.autismspeaks.org/family-services/tool-kits](https://www.autismspeaks.org/family-services/tool-kits)
- National Institutes of Health
- First Signs (public awareness)
  - [www.firstsigns.org](http://www.firstsigns.org)
- CDC/AAP (Act Early)
  - [www.cdc.gov/actearly](http://www.cdc.gov/actearly)
Resources and References
Medical Home

- https://www.medicalhomeportal.org/clinical-practice
- American Academy of Pediatrics
  - https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx
- https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx
- https://medicalhomeinfo.aap.org/Pages/default.aspx

Resources and References
Other

- Birth to Five: Watch me Thrive
What’s Next?

SNI / OHE Collaboration
ASD Webinar Series

• Part I: Overview
   Available on-demand:
   optumhealtheducation.com/autism-part-I-2018
• Part III: Genetics and ASD
   Registration open:
   optumhealtheducation.com/autism-part-III-2018-reg
• Part IV: Treatment Strategies
• Part V: Dual Diagnosis of Down syndrome and ASD
• Part VI: Transition to Adult Care
Thank you

Q&A