

Viewing Time

The program will take up to one hour to complete.

Faculty Disclosure

Robin Campbell, OTR, Gerald Rosen, MD, Jennifer Kaiser, MSW, Melissa Winger, and James Moore, MD have disclosed no actual or potential conflict of interest in relation to this educational activity.

During this educational activity the presenters will not be discussing the use of any commercial or investigational product not approved for any purpose by the FDA.

Target Audience

This program is designed for primary care physicians.

Other health care professionals working with patients and their families may also find this program of interest.

First-Line Care for the Child with an Autism Spectrum Disorder

James Moore, MD

Developmental - Behavioral Pediatrics

Robin Campbell, OTR

Occupational Therapist

Gerald Rosen, MD

Medical Director, Sleep Disorders Program

Melissa Winger

Parent Volunteer

Jennifer Kaiser, MSW

Clinical Social Worker

Children's Hospitals and Clinics of Minnesota

Faculty Disclosure

It is the policy of Children's Hospitals and Clinics of Minnesota to ensure balance, independence, objectivity, and scientific rigor in all its educational programs. Our faculty have been asked to disclose to our program audience any real or apparent conflicts of interest related to the content of their presentation. They have also been requested to let you know when any product mentioned in their presentation is not labeled for the use under discussion or is still under investigation.

First-Line Care for the Child with an Autism Spectrum Disorder

A lecture presenting sensory processing differences commonly encountered in children with autism spectrum disorders, effective strategies for management of their sleep disturbances, as well as describing necessary steps for helping families apply for state and county programs.

Program Objectives

Upon completion of this program, participants should be able to:

- Describe sensory processing differences commonly encountered in children with autism spectrum disorders.
- Identify two effective strategies for management of sleep disturbances in children with autism spectrum disorders.
- Describe the necessary steps for helping families apply for state and county programs.

Receiving CME Credit

To receive CME credit you must view the entire program and complete the evaluation form at the end.

Disclaimer

Children's Hospitals and Clinics of Minnesota accepts no responsibility for the materials presented through these Grand Rounds seminars. Each professional host assumes all responsibility for maintaining confidentiality or obtaining authorization, in accordance with all applicable laws.

First-Line Care for the Child with an
Autism Spectrum Disorder

Sponsored by the Autism Spectrum
Disorders Workgroup

Children's Hospitals & Clinics

Accreditation

Children's Hospitals and Clinics of Minnesota is accredited by the Minnesota Medical Association to provide continuing medical education for physicians. Children's Hospitals and Clinics of Minnesota designates this educational activity for a maximum of 1 AMA PRA Category 1 Credits™ toward the AMA Physician's Recognition Award. Each physician should only claim those credits that he/she actually spent in the activity.

*Autism spectrum disorders workgroup
Children's Hospitals & Clinics*

The mission of the ASD workgroup is to ensure that the care provided for patients with autism at Children's Hospitals & Clinics meets the standard of high-quality, family-centered care provided for patients with any other diagnosis.

James Moore, MD, Robin Campbell, OTR, Gerald Rosen, MD, Melissa Winger, and Jennifer Kaiser, MSW
First Line Care of the Child with Autism

*Autism spectrum disorders workgroup
Children's Hospitals & Clinics*

*Jennifer Anderson	*Veneta Lykken
Elaine Arion, RN	*Ginny Kistler, RD
Carina Bruner, Patient Educator	Dan McLellan, MD
Robin Campbell, OTR	Jim Moore, MD
*Amy Dawson-Moore (PACER)	Anastasia Sullwold-Ristau, PhD
Regina Driscoll, PhD	*Lisa Sieben (AUSM)
Jennifer Kaiser, MSW	Mary Zielinski, PhD
Jeri Kayser, Child Life	(* signifies parent member)

First-Line Care for the Child with an Autism Spectrum Disorder

- Understanding sensory processing differences in children with autism spectrum disorders
Robin Campbell, OTR
- Managing sleep problems in children with autism spectrum disorders
Jerry Rosen, MD
- Caring for the family of the child with an autism spectrum disorder
Veneta Lykken & Melissa Winger (parents)
& Jennifer Kaiser, MSW

First-Line Care for the Child with an Autism Spectrum Disorder

"Identification and Evaluation of Children with Autism Spectrum Disorders" Pediatrics, 2007; 120:1183-1215.

"Management of Children with Autism Spectrum Disorders" Pediatrics, 2007; 120:1162-1182.

First-Line Care for the Child with an Autism Spectrum Disorder

The primary goals of treatment are . . .

- * To maximize the child's ultimate functional independence and quality of life
- * To minimize core autism spectrum disorder symptoms
- * To facilitate development and learning
- * To promote socialization
- * To reduce maladaptive behaviors
- * To educate and support families

American Academy of Pediatrics 2007

Sensory Processing Differences in Children with Autism Spectrum Disorder

Minneapolis and St. Paul, MN

April 15 and 17, 2008

Robin Campbell, OTR/L



Delivering Next Generation Care



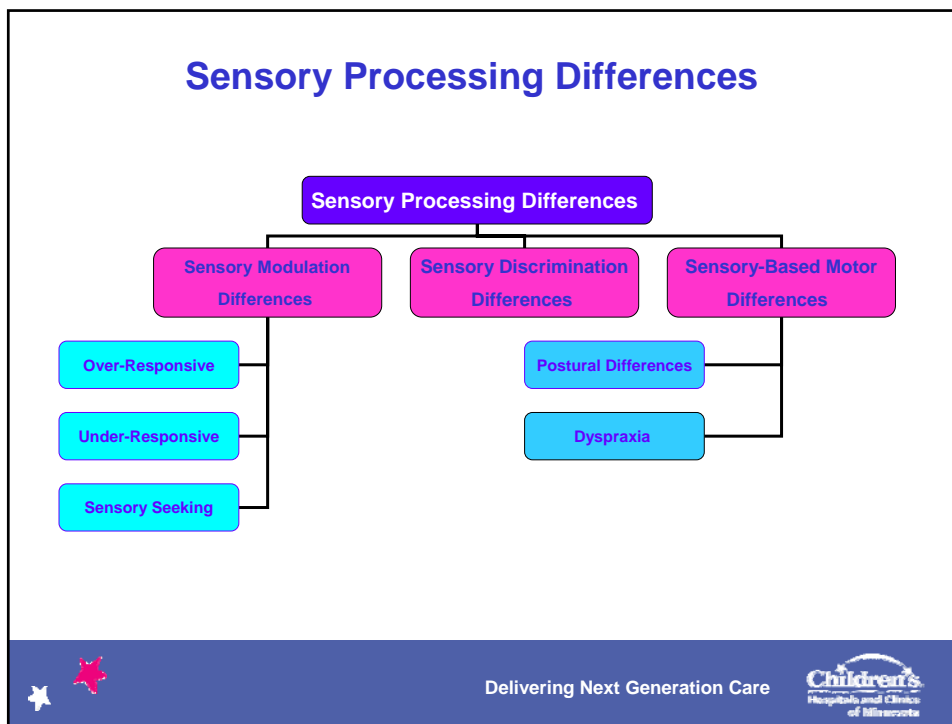
What is Sensory Processing?

- “Sensory Processing” refers to our ability to take in information through our senses, screen, organize and interpret that information in order to make an adaptive response appropriate to the demands of our environment.
- Sensory processing provides the foundation for self-regulation, social-emotional, motor, cognitive, communication and other life functions.



Delivering Next Generation Care





Defining Terms

Sensory Modulation : Ability to regulate and organize responses to sensations from our body and the environment in a graded and adaptive manner over time

Over-Reactive: Low threshold for response to sensation, tends to avoid sensation, hyper-responsive, defensive

Under-Reactive: High threshold for response to sensation, needs increased intensity, duration to register sensation, may be under-aroused or show high sensory seeking to meet needs

Dyspraxia: Difficulty initiating, organizing and executing new and sequential motor actions

Delivering Next Generation Care

Children's Hospitals and Clinics of Minnesota

Sensory Differences in ASD

- **Research and personal accounts by parents and adults with high-functioning autism consistently describe unusual sensory perceptions and reactions across multiple modalities.**
- **Many individuals have difficulty shifting attention between stimuli and attending to and integrating input from more than one sensory modality at a time.**
- **Perceptual differences are unique to the individual and vary from mild to severe**
- **Differences are most evident in early childhood but can remain a lifelong characteristic with significant impact on quality of life.**



Delivering Next Generation Care



Differences in ASD

- **Differences in processing sensory and motor information contribute to core features of social communication deficits and restrictive behaviors**
- **Differences in sensory processing can contribute to anxiety and anxiety in turn exacerbates sensory differences**
- **Differences in sleep-wake regulation also affects sensory responsiveness and contributes to attentional and behavioral challenges.**



Delivering Next Generation Care



Tactile Differences

OVER-RESPONSIVE:

- Unexpected touch may result in outburst or aggressive response, child may avoid proximity to other children, gestures of affection perceived as overwhelming – impacts relationship development, play and development of social communication
- May show strong resistance to daily cares (diapering, bathing, toothbrushing, face washing, hair cares, dressing)
- May avoid exploration of objects with hands, messy play activities and restricts exposure to new sensory experiences

UNDER-RESPONSIVE:

- Seeks intense input, frequently touches objects, people
- Decreased awareness pain, temperature

“As a child I wanted to feel the comfort of being held, but then I would shrink away for fear of losing control and being engulfed when people hugged me.” Temple Grandin



Delivering Next Generation Care



Sound Sensitivity (Over-Responsive)

- 70-85% extreme sensitivity to sound may lead to acting out, avoidant behaviors, “tuning out” and appearing “deaf”, increased anxiety with resistance to participation in normal daily activities
- May react negatively to sudden, unexpected sounds (dog barking, fire alarm, loud laughter, balloon popping)
- May react negatively to high-pitched, continuous sounds (toilet flush, vacuum, hand dryer, blender)
- May have difficulty with complex or multiple sounds (group of people talking, crowded places, cafeteria, gym, auditorium)
- “ When I was confronted with loud or confusing noise I could not modulate it. I either had to shut it all out and withdraw, or let it all in like a freight train. To avoid its onslaught, I would often withdraw and shut the world out.” Temple Grandin



Delivering Next Generation Care



Visual Differences

OVER-RESPONSIVE:

- May use peripheral vision, eye contact perceived as too intense
- May show sensitivity to bright lights, sunlight, fluorescent lights (pulse), loud colors/patterns, visually busy setting may be distressing, lead to shut-down or tantrum

UNDER-RESPONSIVE:

- May show preoccupation with looking at details of objects, edges and rotation of objects - wheels on toy car, revolving fan, open/close doors
- May flick fingers in front of eyes, press eyes



Delivering Next Generation Care



Taste and Smell

OVER-RESPONSIVE:

- May eat restricted diet, show limited food preferences related to taste, texture, temperature, odor sensitivities and desire for sameness (visual presentation)
- May react negatively to perfume, deodorant, cooking odors and common environmental odors

UNDER-RESPONSIVE:

- May seek strong odors and tastes, smear feces
- May show unusual need to smell people and things, mouth/chew non-food items



Delivering Next Generation Care



Vestibular Sense

OVER-RESPONSIVE:

- Insecure with feet off ground, fearful of playground equipment, rides, elevators, car rides
- Restricts movement and active play experiences
- Distressed with imposed movement and change of position
- Becomes disoriented, loses balance
- Shows autonomic responses to movement (flushing, blanching, dizziness, nausea, vomiting)

UNDER-RESPONSIVE:

- Decreased awareness of position and movement in space, decreased balance responses
- Difficulty sustaining posture due to low postural tone, fatigues
- May seek intense movement input including spinning, twirling, running and inverted head position



Delivering Next Generation Care



Proprioceptive Sense

OVER-RESPONSIVE:

- Dislikes feeling of imposed pressure, close relationship w/ tactile system
- Avoids new motor challenges, light grip on objects, avoids weightbearing and position changes in early development, avoids chewy, crunchy foods

UNDER-RESPONSIVE:

- Poor awareness of body movement and position
- Frequently falls, trips, bumps into objects
- Frequently breaks toys, decreased modulation of force, pressure, rhythm
- Lacks body scheme, sense of self, poor basis for gestural imitation/reciprocity
- Limited variety of actions on objects, limited play skills
- May crave intense pressure input – crashes, falls on purpose, climbs, jumps, bounces on toes, flaps arms, chews on non-food items



Delivering Next Generation Care



Postural and Motor Differences in ASD

- Immature movement patterns
- May appear clumsy, awkward run, lack arm swing
- May have decreased postural tone and balance
- Have difficulty establishing and sustaining rhythms, reciprocal movements with others
- Have difficulty planning complex motor sequences
- Difficulty with ball skills and playground games
- Difficulty with imitation skills
- May have immature grasp with tools
- Difficulty with handwriting and fastening
- Difficulty initiating and regulating movements – starting, stopping, modulating force



Delivering Next Generation Care



General Strategies

- Establish regular daily routines
- Modify environment to reduce sensory overload
- Allow extra time to process information, use “low and slow” communication
- Provide visual supports for organization and communication
- Provide enhanced sensory experiences to engage, support attention, interaction and self-regulation
- Provide quiet space for regrouping
- Prepare for change in routine, transitions, sensory challenges
- Break down tasks and practice skills
- Use special interests to motivate, support learning
- Schedule and allow for movement breaks



Delivering Next Generation Care



Some Sensory Supports

- Firm touch pressure is usually tolerated better than light touch
- Prepare for touch, give space, don't approach rapidly
- Provide opportunities for deep touch pressure if tolerated – massage, pressure down over shoulders, sit in bean bag chair/cushions, press body with cushions, provide fidget toys/objects to hold/touch, weighted materials, chew/bite against resistance
- Investigate individual responses / behaviors to plan supports
- Reduce noise or try rhythmic background music, headphones, earbuds if tolerated, use white noise machine in bedroom to block out sounds
- Reduce visual clutter, use visual supports (PECS, schedules), position away from glare of sunlight, dim lights, use incandescent lighting, use sunglasses, soft colors
- Make systematic small changes to increase flexibility and willingness to try new activities, tastes, textures, etc.
- Explore with and teach strategies to family and other providers, develop sensory diet activities that support self-regulation



Delivering Next Generation Care



Supporting Needs of Families and Children with ASD

- Family First in Our Efforts
- Family Resource and Support Center
- Developmental Pediatric Clinic
- Psychological and Social Services
- Rehabilitation Services- Speech, Occupational and Physical Therapy
- Feeding Clinic
- Child Life Services
- Autism Task Force Work Group
- Collaboration with Community Providers



Delivering Next Generation Care



Sleep in Children with Autism

Gerald Rosen
 Childrens Hospitals and Clinics



- ### Prevalence of Sleep Symptoms (5-7 days/week)
- 54-86% (questionnaire based)
 - Co-sleeping - 16%
 - Bedtime resistance – 54%
 - Insomnia – 56%
 - Parasomnias – 53%
 - Sleep disordered breathing – 25%
 - Morning rise difficulty – 45%
 - Daytime sleepiness – 31%

- ### Co-morbid problems in children with autism
- Hyperactivity
 - Aggressiveness
 - Fearfulness
 - Anxiety
 - Depression
 - Heightened sensitivity to touch
 - Seizures
 - Obsessive-compulsive disorder
 - Psychotropic medications

- ### Causes of sleep problems autism
- Circadian rhythm disorders
 - Poor sleep hygiene
 - Irregular sleep schedule
 - Sleep insufficiency
 - Environmental sleep disorder
 - Anxiety/depression
 - Sleep disordered breathing/CPAP is difficult
 - Seizures
 - Medications

Sleep Process Matrix

Sleep Process	Circadian	Homeostatic	Ultradian	Developmental	Cardio-respiratory	Neuro	Psych / Behavior	Drugs / Alcohol	Other/ Medical
Hypothesis									
Data to Gather									
Analysis									
Synthesis									
Treatment									

Treatment of sleep problems in autism

- **Sleep hygiene – this is very important and needs to be the first step**
 - Correct bedtime
 - Pleasant, relaxing bedtime ritual not in bedroom
 - Limit electronic media before bedtime
 - Extinction of unwanted behaviors
 - Regular bedtime/waketime
 - Naps – limited and consistent
 - No caffeine
 - Morning bright light exposure
 - Daytime exercise

Sleep in autism

- Decreased melatonin secretion

Treatment of sleep problems in autism - behavioral

- To begin only after sleep hygiene has been addressed
- Strategy for addressing anxiety
- Teach parents strategy for daytime behavioral problems before night time

Treatment of sleep problems in autism – other medications

- Sedative hypnotics have not been evaluated
 - Sedating antidepressants, atypical antipsychotic often used
- If risperidone for behavior problems consider a bedtime dose
- If daytime stimulants monitor long acting preparations for insomnia & give early

Treatment of sleep problems in autism - Melatonin

- Increases sleep duration
- Decreases awakenings
- 3-9 mg at bedtime
- If DSPS also give 1 mg melatonin at 6 pm

Psychotropic Drugs use in Autism

- 56% used 1 drug
 - ages 0-2, 18%
 - ages 12-18, 67%
- 20% >3 drugs
- Most commonly prescribed
 - Neuroleptics – 31%
 - Antidepressants – 25%
 - Stimulants – 22%

Autism in the Hospital, Clinic, and at Home

Grand Rounds
April 2008

*Veneta Lykken, Family Advisory Council
Melissa Winger, Parent Volunteer
Jennifer Kaiser, MSW, LICSW*

Responses to Medical Situations

- Communication problems
- Presents misleading indicators of agreement or disagreement
- Tendency to wander away
- May become loud and/or aggressive
- May not tolerate an exam
- May “shut down”

A Parent's Perspective: *Working with Autistic Patients.*

Community Supports:
What are they?

Sensory Overload

- Hospital/Clinic is filled with stimulation
- Calm creates calm
- Move child to a quiet space
- Dim lights
- May need several visits to familiarize routine



Characteristics

- Little to no eye contact
- Unable to provide reliable information
- Sensory overload
- Unable to follow directions
- Highly agitated


Suggestions for Staff

- Listen to parents/caregivers
- Give child time to calm down
- Try to avoid touching
- Use smaller/simple words
- Use pictures and/or symbols




County Resources


- **Health Care:**
 Medical Assistance - MN Care
 TEFRA



- **Community Based Services:**
 County Waivers
 Case Management Services




Delivering Next Generation Care




Community Based Services

Waivers

- **Community Alternative Care (CAC):**
 For chronically ill/medically fragile persons who need the level of care provided in a hospital.
- **Community Alternatives for Disabled Individuals (CADI):** For persons with disabilities who require the level of care provided in a nursing facility.
- **Developmental Disabilities (DD):** For persons with mental retardation or a related condition who need the level of care provided in an Intermediate Care Facility.



Delivering Next Generation Care



Health Care

- **Medical Assistance (MA)** is Minnesota's Medicaid program. It provides health care coverage for low-income people with disabilities and/or children.
- **Minnesota Care** is a subsidized health insurance program for Minnesota residents who do not have access to affordable health care coverage.

**Who Is Eligible?
 How Do I Apply?**





Delivering Next Generation Care




Community Based Services

- **Each waiver program includes:**
 - Eligibility requirements specific to the type of disability.
 - Funding parameters and limits.
 - Separate county and/or state policies.
 - Service menus.





Delivering Next Generation Care




Health Care

- **TEFRA** – Allows some children with disabilities who live with their families to be eligible for Medical Assistance without counting parent's income.


A child must meet ALL of the following:

- live with at least one parent,
- be under 18,
- have a disability determination from the State Medical Review Team,
- need a certain level of home health care to stay at home which compares to the level of care provided in a hospital,
- the cost for home care must not be more than the cost for care in a medical institution.

How Do I Apply?




Delivering Next Generation Care




Community Based Services

- **Case Management Services**
 - Used to help to determine which services meet the needs of the child and the family. Including respite service, family support grants, waived services, or emergency assistance.

How Do I Apply?




Delivering Next Generation Care



Community Agencies

- Washburn Child Guidance Center
- Fraser Child and Family Services
- St. David's Child Development & Family Services
- Pacer Center
- School District – Special Education Services.

Delivering Next Generation Care 

Community Agencies

- **St. David's Services**
 - Autism Day Treatment Program – Designed for children ages 18 months to 5 years old on the Autism Spectrum to include Mental Health services, OT, PT, SLT, and Music.
 - Morning or Afternoon sessions offered.
 - Funded by insurance, MA, Private Pay


Contact Information: 952-548-8680

Delivering Next Generation Care 

Community Agencies

- **Washburn Child Guidance Center**
 - Outpatient counseling – Individual and family therapy.
 - Outreach – Training, consultation, and screening services for child care centers and preschool programs.
 - Family Focused Preschool/Infant/Toddler Program – Serves kids ages birth – five who are at-risk for abuse due to high levels of family stress. In-home therapy and case management.


Some programs specific to Hennepin County

Delivering Next Generation Care 

Community Resources

- **Pacer Center**
 - Early Childhood Intervention
 - Emotional and Behavior Disorders (EBD) and Children's Mental Health Services
 - Health Information and Advocacy Center
 - Parent to Parent Support Project
 - Parents Helping Parents

Pacer Contact # 952-838-9000

Delivering Next Generation Care 

Community Agencies

- **Fraser Child and Family Services**
 - Diagnostic Evaluations
 - Comprehensive mental health services – therapy
 - Rehabilitation services – PT, OT, SLT, and Music
 - Child Care and Education for kids with special needs.
 - Workshops and seminars for parents, caregivers, and professionals.

Referrals? Contact intake at 612-331-9413

Delivering Next Generation Care 

Community Resources

- **Special Education Services**
 - Early Intervention Services
 - Individualized Education Plan (IEP)



Delivering Next Generation Care 

James Moore, MD, Robin Campbell, OTR, Gerald Rosen,
MD, Melissa Winger, and Jennifer Kaiser, MSW
First Line Care of the Child with Autism

Questions?

Veneta Lykken: veneta@aol.com

Melissa Winger: melissa.winger@childrensmn.org

Jennifer Kaiser: jennifer.kaiser@childrensmn.org

Autism Society of Minnesota: www.ausm.org

Autism Speaks: www.autismspeaks.org



Delivering Next Generation Care



*Thanks for viewing
this presentation!*



*To receive CME credit, please click
the CME Eval button below
and complete the form.*