How to Identify Health Risks of the IDD Population

Elizabeth Cooper, RN-BC
Marion Oliver, MSW
Goal

Identify specific health and behavioral risks associated with intellectual and developmental disability diagnoses
Topics of Discussion

• Health Risk Indicators
• Behavioral Risk Indicators
• Medical Conditions with Behavioral/Psychiatric Implications
• Behavioral Symptoms with Clinical Implications
Health Risk Indicators

- Live with complex health conditions
- Have limited access to quality healthcare and health promotion programs
- Missed cancer screenings
- Have poorly managed chronic conditions, such as epilepsy
- Obesity
- Have undetected poor vision
- Have mental health problems and use psychotropic medications
Specific Health Risk Indicators

- Repeat hospitalizations for the same diagnosis
- Multiple emergency room visits
- Increased use of tube feeding
- Increase or change in seizure activity
- Conditions that impair mobility
- Repeat or multiple fractures
- Multiple vomiting or aspiration events
- Coughing, choking at mealtime
- Significant change in eating habits or weight loss
- Recurrent gastrointestinal disorders
Specific Health Risk Indicators (continued)

<table>
<thead>
<tr>
<th>Health Risk Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infections that do not respond to treatment</td>
</tr>
<tr>
<td>Changes in elimination patterns</td>
</tr>
<tr>
<td>Changes in skin integrity</td>
</tr>
<tr>
<td>Increased use of oxygen/suctioning</td>
</tr>
<tr>
<td>Increased time spent bedridden</td>
</tr>
<tr>
<td>Decreased motor abilities</td>
</tr>
<tr>
<td>Alterations in mental status</td>
</tr>
<tr>
<td>Obesity</td>
</tr>
<tr>
<td>Inability to access necessary medical care</td>
</tr>
<tr>
<td>Multiple physicians</td>
</tr>
<tr>
<td>(These are not limited to this list)</td>
</tr>
</tbody>
</table>
Individuals with IDD may demonstrate challenging behaviors as a means of communicating need, as a symptom of a mental health disturbance, or as a symptom of neurological condition.

Challenging behaviors can lead to:

- Self harm
- Physical injury to others
- Destruction of property
- Limited community involvement
- Disadvantages
Psychotropic medication prescribed for the followed reasons:

- Stripping, elopement, and cursing
- Staff or family convenience
- Without any diagnosis (in this case, even behavioral problem qualifies)
- Medications often prescribed for these reasons qualify as abuse and/or forms of chemical restraints.

* Not limited to this list.
Frequently Diagnoses Neurological Conditions of the IDD Population
Tuberous Sclerosis (TSC)

Tuberous sclerosis is described as a triad of neurologic impairments, multisystem hamartomas (benign tumors that grow in the brain and on other vital organs), and skin findings (ash leaf macules and facial angiofibromas).

Health Risks
- Autosomal dominant genetic disorder
- Renal failure caused by Angiomyolipomas
- Surgery may be required to remove tumors
- Seizures common, 20% Lennox-Gestaut
- Intellectual Developmental Disability
- Generally diagnosed in first year of life; infantile spasms

Behavior Risks
- Aggression
- Self harm
- Mood swings
- Sleep difficulty
- Features of Autism
Spina bifida is a birth defect (lack of folic acid in developing fetus) that occurs when the spine and spinal cord don't form properly. Spina bifida can occur as:

Spina bifida occulta- The mildest form resulting in a small separation or gap in one or more of the bones of the spine.

Meningocele- The protective membranes around the spinal cord (meninges) push out through the opening in the vertebrae.

- Sac filled with fluid; doesn't include the spinal cord.

Myelomeningocele- most severe form. The spinal canal is open along several vertebrae in the lower or middle back.

- The membranes and spinal cord or nerves protrude at birth, forming a sac. Tissues and nerves are usually exposed, though sometimes skin covers the sac.
HEALTH RISKS:

• Tethered cord; most common in Meningocele, and Myelomeningocele
• Loss of muscle function to the legs
• Changes in bowel and bladder function, skin breakdown
• Subsequent surgeries to manage problems with the feet, hips, or spine
• Learning disabilities are predominant, possible Intellectual Developmental Disability

BEHAVIOR RISKS:

• Possible memory, comprehension, and attention deficits
• Depression and generalized anxiety
Fragile X syndrome is a genetic disorder that affects a person's development, especially a person's behavior and ability to learn. Physical features may include a long, narrow face, large ears and large testicles.

**Health Risks**
- Males affected most commonly
- Difficulty with feeding, vomiting, gastroesophageal reflux resulting in “Failure to thrive”
- Most commonly diagnosed inherited Intellectual Developmental Disability

**Behavior Risks**
- Sensitivity to sensory stimuli and a tendency towards hyperarousal
- Loss of capacity for self-regulation
- Aggressive outbursts or self-abusive behaviors
- Features of Autism
**Autism Spectrum Disorder**

Difficulty with communication and interaction with other people. Restricted interests and repetitive behaviors.

**HEALTH RISKS:**
- Allergies or asthma and gastrointestinal disorders
- Metabolic disorders such as diabetes; heart disease
- Seizures are common
- Aversion to various food textures
- Sleep disturbance

**BEHAVIOR RISKS:**
- Flapping of arms, rocking from side to side
- Preoccupied with parts of objects
- Maladaptive emotional expression
- Tactile defensive
- Asperger syndrome; an Autism Spectrum Disorder characterized by significantly difficult social interaction, nonverbal communication with restricted and repetitive patterns of behavior and interest
Rett Syndrome

A rare genetic neurological and developmental disorder that affects the way the brain develops, causing a progressive inability to use muscles for eye and body movements and speech. It occurs almost exclusively in girls.

Health Risks
- Seizures
- Scoliosis
- Cardiac arrhythmias
- Cerebral Atrophy-early Dementia

Behavior Risks
- Jerky trunk ataxia
- Hand wringing/clapping
- Sleep disturbance
- Vacant facial expression
Down Syndrome

Extra copy of chromosome number 21 (Trisomy 21), which is a genetic disorder, varies in severity causing lifelong intellectual and developmental disabilities.

HEALTH RISKS:
• Hypothyroidism
• Congenital heart problems
• Risk for Acute Leukemia
• Atlanto-axial instability

BEHAVIOR RISKS:
• Increased risk of Dementia
• Depression and generalized anxiety
• Repetitive and obsessive-compulsive behaviors
• Oppositional and inattentive behaviors
Fetal Alcohol Syndrome

The range of effects that can occur in an individual prenatally exposed to alcohol resulting in facial anomalies (small eyes, thin upper lip, small head, large ears), growth deficiency, and central nervous system deficits.

Health Risks

• Heart defects
• Failure to thrive
• Deformities of hands and fingers
• Intellectual Developmental Disability

Behavior Risks

• Maladaptive social skills
• Difficulty staying on task and controlling impulses
• Difficulty with reasoning, problem solving, and memory
• Rapidly changing moods, hyperactive
Cerebral Palsy

A condition that is permanent, but not progressive. Cerebral palsy is a life-long physical disability due to damage of the developing brain.

HEALTH RISKS:
• Seizures
• Hearing impairment
• Dysphagia/Intellectual Developmental Disability

BEHAVIOR RISKS:
• Depression/Social withdrawal
• Difficulty with speech and communication
• Maladaptive coping strategies
• Frustration with life stressors and daily challenges
Prader-Willie Syndrome

Rare genetic defect caused by an abnormal 15th chromosome present at birth and results in distinct facial features (almond-shaped eyes, narrowing of the head at the temples, turned down mouth, thin upper lip), mental and behavioral disabilities.

HEALTH RISKS:
- Failure to thrive-poor sucking reflex (as infants)
- Food cravings and weight gain (in early childhood to adulthood)
- Short stature, small hands and feet, obesity related complications
- Difficulty regulating body temperature
- Underdeveloped genitals
- Intellectual Developmental Disabilities

BEHAVIOR RISKS:
- Obsessive thinking
- Difficulty with communication
- Anger and aggression, especially if denied food, insatiable appetite
- Sleep difficulty
Summary

Compared to the general population, adults with intellectual or developmental disabilities:

- Have the same or greater health risks, except less likely to smoke
- Are more likely to lead a sedentary lifestyle
- Are less likely to have emotional support
- Experience poor health more often
- Are more likely to be obese
- Lack of physical activity and obesity are risk factors for:
  - Cardiovascular disease
  - Diabetes
  - High blood pressure
  - Cancer
  - Sleep difficulties
  - Joint problems
Our Goals

- Integrate health promotion into community environments
- Increase knowledge and understanding
- Improve quality of healthcare
- Train healthcare providers
- Ensure effective healthcare financing
- Increase sources of healthcare
Our Goals

- Education to staff on specific health risks
- Ensure people have needed behavioral supports
- Advocate for quality health providers
- Educating staff on specific health risks
- Advocate for quality health providers who listen and respond to the person's health and wellbeing needs
Closing the Gap

- Once, disability was considered incompatible with health.

- Public health now recognizes that:
  - “disability” and “health” are not mutually exclusive
  - disability can be complicated by secondary health conditions
  - health promotion efforts are needed to improve health outcomes for persons with disabilities
  - Now recognized need for disability identifiers on surveillance tools
Thank you

For Georgia Collaborative ASO general inquiry or questions please email:

GACollaborativePR@beaconhealthoptions.com