A Guide for Caregivers
An Approach to the Evaluation and Treatment of Challenging Behaviors
In Young Adults with Intellectual Disability/Developmental Disability

Incorporates Vignettes that Illustrate Practical Solutions

Nienke P. Dosa MD, MPH • Susan Scharoun PhD

healthytransitionsny.org
Dear Caregivers,

“Dual diagnosis” is a term that is used when a person with a developmental disability also has a mental illness. It is often hard to diagnose a mental illness in a person who has a developmental disability. However, in order to provide effective treatment, it is very important to differentiate symptoms of a mental disorder from behaviors associated with the developmental disability.

A person who has a developmental disability may have a difficult time conveying accurate information at the time of an assessment. Parents, siblings, or even direct support staff and other service providers can be valuable resources in defining the symptoms and identifying behaviors of concern. This guidebook gives caregivers the tools they need to understand how mental illness might look in a person with a developmental disability, and information on what to do and where to go for help. It was written in order to help caregivers to partner with health care providers. This guidebook was originally written in 2011 and was revised in 2015. It was created for the New York State Institute for Health Transition Training with grant support from the New York State Developmental Disabilities Planning Council. We hope that this guidebook will be helpful to people with developmental disabilities and their families. For more information about this project, and to contact us, please visit http://healthytransitionsny.org.

Sincerely,

Nienke P. Dosa MD, MPH
Susan Scharoun PhD

Dr. Dosa is a developmental pediatrician at SUNY Upstate Medical University and medical director of the Spina Bifida Center of Central New York. She currently holds the Upstate Foundation Professorship in Child Health Policy and is a Senior Fellow at Syracuse University’s Burton Blatt Institute. Her academic interest is the development and evaluation of community-based models for developmental disability care. Her work is focused on transition to adulthood and inclusive fitness across the lifespan. She is director of the New York State Institute for Health Transition Training (HealthyTransitionsNY.org) and a founding member of Central New York’s Fitness Inclusion Network (FitnessInclusionNetwork.org).

Susan Scharoun, Ph.D. Professor of Psychology at LeMoyne College in Syracuse, NY. She teaches undergraduate courses in Brain and Behavior, The Psychology of Disabilities, Motivation and Emotion, Human Lifespan Development and Disorders of Childhood. Dr. Scharoun has over twenty years of experience working with children and adults who have developmental disabilities in residential, vocational, academic and home settings. She is also a sibling of a person with a developmental disability.
The comprehensive evaluation and treatment of behaviors in an individual with a developmental disability can be challenging. It is important to identify whether behaviors are coming from intellectual disability, mental illness, or an interaction between the two. It is very important to consider all possible causes for a behavior, before labeling or dismissing an issue or concern as “behavioral.”

Unfortunately it is not unusual for an individual with an intellectual disability, who in fact should be considered as dual-diagnosed, to be referred to a behavior management program without receiving psychiatric evaluation or treatment. Non-psychiatric medical causes for escalating behaviors are also often overlooked. Undiagnosed pain syndromes such as a dental abscess, constipation, or even mild conditions such as allergy or dry skin can result in challenging behaviors. When psychiatric or medical conditions go undiagnosed, the individual is not given the opportunity to recover. This is because the root of the problem is being overlooked. A thorough assessment is essential to making a diagnosis and to providing effective treatment, services and supports.

The table on page 2 outlines a strategy for Comprehensive Evaluation and Treatment of Behaviors in People with Developmental Disabilities. It lists medical and non-medical factors that should be considered when an individual with a developmental disability has escalating behaviors. This table can be used to guide a diagnostic work-up and to monitor the effectiveness of treatment. A thorough assessment of both physical health and mental health are book-ends to this suggested approach. The table also highlights non-medical causes, such as “learned” behaviors, sensory problems, change in routine, inadequate communication, caregiver stress, and issues related to quality of life. These non-medical factors often contribute to escalating behaviors. However, it is essential to first rule out all possible medical causes, including treatable pain syndromes. The figure on page 3 is a Body Map of Common Pain Syndromes that should be considered as part of any thorough medical evaluation of escalating behaviors in a person with a developmental disability.
### CHALLENGING BEHAVIORS

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#### Describe Behavior

- **Learned Behavior**
  - Dysfunctional behavior that is "rewarded" with attention or that gets the individual out of a non-preferred activity
  - **Medical Care**
  - Functional Behavioral Assessment
  - Behavior Management Plan
  - Promote Positive Behaviors

- **Sensory Issues**
  - Intolerance to noise level, lighting, crowded situations, temperature, etc.
  - **Occupational Therapy Evaluation**
  - Sensory Diet

- **Change in Routine**
  - New aide, program, location, transportation, etc.
  - Visual Schedule
  - Social Stories
  - Counseling

- **Inadequate Communication**
  - Frustration due to inability to communicate effectively
  - Speech/Language Evaluation
  - Augmentative and Alternative Communication (AAC)

- **Caregiver Stress**
  - Physical exhaustion
  - Sleep deprivation
  - Financial stress
  - Marital distress
  - Social isolation
  - Psychiatric condition
  - Respite
  - Counseling
  - Circle of Support
  - Medical Treatment
  - Psychiatric Care

- **Quality of Life**
  - Social isolation
  - Lack of exercise
  - No outdoor activities
  - Self Determination
  - Circle of Support

- **Mental Health**
  - **Psychiatric Care**

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### Evaluate & Diagnose

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<th>Physical Health</th>
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### Quality of Life

- Social isolation
- Lack of exercise
- No outdoor activities

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**Mental Health**


Body Map of Common Pain Syndromes

- Sinusitis
- Allergies
- Dental Caries or Abscess
- Tonsillitis
- Joint Pain
- Muscle Strain
- Fracture
- Dry Skin (seasonal)
- Contact Dermatitis
- Premenstrual Dysphoria
- Menstrual Cramps
- Testicular Torsion
- Joint Pain
- Muscle Strain
- Fracture
- Bunion
- Blister
- Ingrown Toenail
- Athletes Foot

- Headache (stress, migraine)
- Glaucoma
- Corneal Abrasion
- Foreign Body
- Ear Infection
- GERD
- Food Intolerance/Allergy
- Gastric Ulcer
- Gall Stones
- Small Bowel Obstruction
- Constipation
- Appendicitis
- Volvulus
- Kidney Stones
- Urinary Tract Infection
- Dry Skin (seasonal)
- Contact Dermatitis
- Bunion
- Blister
- Ingrown Toenail
- Athletes Foot
Multiple factors can contribute to any given situation. All potential causes for escalating behaviors should be considered and addressed systematically. Frequent re-assessment is essential for accurate diagnosis and comprehensive treatment. This iterative process begins with a detailed description of the behavior of concern using a process called A-B-C charting to identify the cause(s) of a behavior.

**A-B-C CHARTING**

A-B-C stands for antecedent-behavior-consequence. A-B-C charting begins with the identification of a target behavior. This is typically a behavior that has been identified as inappropriate, harmful, or maladaptive and in need of modification. The next step is to look closely at, and systematically keep track of, the antecedents of the behavior (what happened just prior to the display of the target behavior) as well as the consequences of the behavior (what happens right after a behavior). The consequence is often a powerful reinforcement. A-B-C charting is done over several days and in multiple settings in order to identify a pattern. An A-B-C chart is included on page 5. More information about A-B-C charting is provided on page 10: An Overview of Functional Behavioral Analysis.

Once a target behavior or pattern of behaviors has been carefully described with A-B-C charting, the Comprehensive Evaluation Table on page 2 can be used to systematically consider medical causes and psychiatric causes, as well as non-medical factors that may be contributing to the situation. This systematic and iterative approach can help to answer whether a behavior is related to physical health or mental health, or due to non-medical causes such as “learned” behaviors, sensory problems, change in routine, inadequate communication, caregiver stress, or issues related to quality of life.
**Antecedent-Behavior-Consequence Chart**

Instructions:
Write down when and where behaviors occur, and what happens right before and right after a behavior. Do this for several days and in a variety of settings. The A-B-C chart can help to identify whether there is a pattern to the behaviors.

<table>
<thead>
<tr>
<th>DATE/TIME</th>
<th>SETTING</th>
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Following are examples for each of the categories listed on the Comprehensive Evaluation Table on page 4.

**PHYSICAL HEALTH**

A thorough medical evaluation should always take place when there are escalating behaviors. First and foremost it is essential to rule out a pain syndrome and to consider all other potentially treatable medical causes. For example, hypothyroidism in a person with Down syndrome may look like the symptoms of depression. Common pain syndromes are summarized in the Figure on page 15. Other medical problems that should be considered and ruled out include blood sugar fluctuations, sleep apnea, progressive vision or hearing loss, substance abuse, seizures, and medication side effects. Any person with epilepsy must be closely monitored for drug interactions and/or side effects.

Crystal is a 17-year old young woman with autism. She is usually calm and has a very pleasant disposition. Lately she has been aggressive, spitting on people and drooling more frequently. A-B-C chart documents that this is a concern across all settings and with multiple caregivers. Crystal’s school nurse reviews the Comprehensive Evaluation Table and the Body Map of Pain Syndromes with Crystal’s physician. A thorough physical exam reveals that Crystal has a dental abscess. Once her dentist has treated this, the spitting and self-striking behaviors disappear.

Sheila is a 14-year old non-verbal adolescent with cerebral palsy and vision impairment. A-B-C chart reveals that she is listless after school on the days that she is cared for at her grandparent’s house. Sheila’s physician reviews the Comprehensive Evaluation Table with Sheila’s grandparents and considers the possibility that this is due to low blood sugar. This is because Sheila’s grandparents give Sheila her snack at a later time than at Sheila’s after school program. The listlessness resolves when Sheila’s grandparents give her a snack as soon as she gets off the bus from school.

**LEARNED BEHAVIOR**

It is important to consider what motivates a person to display a specific behavior. Does s/he want the attention of a caregiver or teacher? Does s/he want to get away from something or someone, for example, an academic demand or a bothersome peer? Does s/he want a tangible object, for example, food or a toy? Does s/he do it because it feels good or is self-reinforcing, for example, rocking or hand flapping? A-B-C charting and a functional behavioral analysis can sort this out. A-B-C charting can also document the effectiveness of interventions that promote positive behaviors.

Nick is a 15-year old with intellectual disability who has a tendency to ruminate. He often places his hand in his mouth as a self-reinforcing behavior. A-B-C chart reveals that this is a major concern in the hallways at school whenever he transfers between classes. A careful physical exam does not reveal a medical cause other than reflux, which is treated. When the behaviors persist, the school psychologist repeats the functional behavioral analysis and reviews the Comprehensive Evaluation Table. A customized behavior management plan is developed for Nick that includes a “competing behavior” that prevents him from putting his hands in his mouth when he walks in the hallway. The solution is simple: Nick is given a backpack to carry between classes. He no longer puts his hands in his mouth, because his hands are needed to carry the backpack. Because this intervention has been so successful, the school psychologist expands this approach by asking Nick to carry the mailbag and deliver mail to classrooms throughout the building. Nick is proud to be given this responsibility. The self-gagging behavior fades. The intervention not only solves the “problem” it also promotes positive behaviors!
SENSORY ISSUES

People with developmental disabilities may process sensory input in different ways. Certain sounds or lighting situations may be intolerable to some. Others may seek sensory input by rocking or spinning. An occupational therapist can identify strategies to minimize these responses. An occupational therapist can also identify ways to adapt the environment so that it is more tolerable to the individual.

Amy is a 21-year old woman with autism who has difficulty adjusting to her new day habilitation program. Amy’s father and an occupational therapist from the OPWDD use A-B-C charting to identify the cause. Amy needs time at the beginning of the day for a vigorous walk and 5-10 minutes in her swing. This is not currently part of the routine at the new day habilitation program. Without this sensory input it is difficult for Amy to focus on other activities. The occupational therapists arranges for the installation of an adapted swing at the day habilitation program. She also talks with the day habilitation staff about the importance of having a sensory “diet” for Amy that includes vigorous walking and swing time at the beginning of the day. Once the sensory diet has been implemented, Amy is better able to participate in structured activities at the day habilitation program.

CHANGE IN ROUTINE

It is common for adolescents to become attached to a favorite one-on-one aide or teacher, and natural for parents to request continuity with staff from year to year. However, young adulthood inevitably bring about a change in routine, due to staffing changes in high school, or upon graduation, when the structure and social context of high school disappears. Anxiety and depression, and/or a deterioration in behaviors can result. Pro-active caregivers and school teams can avoid this very understandable situation by giving adolescents and young adults opportunities to “try out” other settings or routines well before high school graduation. Examples include after school programs, summer camp, overnight stays with relatives, or weekend retreats. These experiences give teens the opportunity to demonstrate both to themselves, and to others, that they are able to handle change. Practice builds confidence. Communication between middle and high school teams, or between high school teams and day-habilitation staff is essential when major shifts in daily routines take place. Social stories, counselling, and giving youths the opportunity to visit, share photos, or otherwise stay in touch and relay their new experiences with a favorite teacher or aide helps to normalize the transition process.

Katherine is a 14 year old with autism who recently transferred from middle school to high school. Katherine’s mother notes that her behaviors have been “off the wall”. School staff are considering placement in a BOCES program, rather than the local high school. After physical and psychiatric causes have been ruled out, Katherine’s mother enlists the help of an educational advocate from a local agency to help sort out the situation. The educational advocate suggests that the team from Katherine’s middle school meet with Katherine’s high school team. This face-to-face meeting is very helpful for all involved. Katherine’s 1 : 1 Aide in particular has helpful suggestions for communication and for staving off behavioral outbursts and for promoting positive behaviors. The school psychologist suggests that the high school team use picture sequences that were created for Katherine at her middle school. The “social stories” that these picture sequences convey help Katherine to better understand, anticipate, and adjust to high school routines. Weekly conference calls between the middle school and high school staff are scheduled until Katherine’s “off the wall” behaviors resolve. The school district decides to implement weekly conferences with the middle school team pro-actively for all incoming high school students who have autism.
INADEQUATE COMMUNICATION

The field of augmentative and alternative communication, and advances in universal design of communication technologies has opened up new avenues for expressive communication for people with developmental disabilities who are affected by autism, specific learning disabilities, apraxia, dysarthria, cerebral palsy and other motor disabilities. It is always important to consider the possibility that an escalating behavior in a person with a developmental disability is simply due to frustration with the limitations of the communication repertoire that is available to that person. The treatment for this situation does not involve medications or behavioral supports. The appropriate approach is a thorough assessment by a qualified augmentative and alternative communication team, and the implementation of a systematic communication plan.

Christopher is a 14 year old adolescent with cerebral palsy who is seen by his physician because he repeatedly bites his wrist. A-B-C charting helps to identify a potential cause: the biting behavior began when the wheelchair mount for his voice output device required repair. In addition, the physician observes that, due to spasticity, Christopher’s elbows are often flexed, such that his wrist is constantly near his mouth. In addition to prescribing medications to treat the spasticity, and recommending a new wheelchair, the physician also writes a prescription for an “Augmentative and Alternative Communication Evaluation”. The speech therapist at school sets up an evaluation with a team that includes a communication specialist, an occupational therapist, and a physical therapist. Eye gaze technology is identified as the most appropriate type of communication device by the “AAC” team. The wrist biting behaviors fade when Christopher has ready access to this communication device.

CAREGIVER STRESS

It is always important to consider family context whenever a person with a chronic condition has an acute change in physical, behavioral, or mental health status. This applies to people with developmental disabilities as well, since many rely on family caregivers to help with day-to-day routines. If a parent or sibling is unable to perform this role for any variety of reasons, the person with a developmental disability may present with behaviors, physical concerns, non-adherence to medications, or a change in hygiene. It is important to ask parents and siblings about caregiver stress, and to provide caregiver support when it is needed. Caregiver stress is predictably greater during times of transition, such as a move to a new home, or when there are unexpected medical complications. These changes do not necessarily directly involve the person with a developmental disability, but can have a significant impact on the ability of family caregivers to provide support.

David is a 16 year old adolescent with Fragile X Syndrome who is brought to the emergency room repeatedly on weekends. His mother brings him in because she states that he has violent outbursts. A-B-C charting reveals that these outbursts occur at home but not at school. David becomes very anxious in the emergency room, acts out, and typically is heavily medicated before eventually being sent back home. An astute social worker spends time with David’s mother during one of these ED stays, and discovers that the mother has a psychiatric condition for which she has stopped taking medications. The social worker follows up with the family to make sure that David’s mother is receiving the psychiatric care that she needs. The social worker also increases David’s respite hours, thereby providing “care for the caregiver” so that David’s mother can recover her health. The frequent emergency room visits stop when the underlying cause is identified and treated.
QUALITY OF LIFE

Consideration of quality of life is central to any approach when caring for a dually diagnosed person. Quality of life expectations (such as outdoor recreation and meaningful social interactions) should be the same for everyone in our society. The needs of people who are dually diagnosed are essentially the same. However, quality of life needs of people with dual diagnosis often become medicalized. The medical model, though essential in treating the symptoms of the mental illness, does not take into consideration the underlying issue so commonly seen in the dually diagnosed, which is a lack of access to quality of life spheres.

Michael is a legally blind 24-year old with intellectual disability who attends a day habilitation program during the week. He is home with his father on the weekends. Michael’s father is concerned that Michael has begun to ruminate. This is an unusual behavior for his son. After a careful physical exam has ruled out medical and psychiatric causes, Michael’s father discusses his concern about rumination with Michael’s service coordinator. Together they visit the day habilitation program. They discover that Michael never has the opportunity to be outdoors at this day habilitation program. Light and sunshine have always been very important to Michael. Because the day habilitation program does not have adequate outdoor facilities, Michael’s service coordinator arranges for Michael and his father to visit several other day habilitation programs, including one that is located on a farm that offers daily outdoor activities throughout the four seasons. In addition, Michael’s service coordinator identifies a recreation therapist to develop a range of outdoor activities for Michael. The rumination becomes a non-issue almost immediately.

MENTAL HEALTH

Questions about mental health in both the person and his or her family should be part of the intake history of persons who are developmentally disabled, particularly in light of the high prevalence of dual diagnosis in this population. Intake forms should have specific questions about mental illness that are routinely asked. As noted previously, the Diagnostic Manual – Intellectual Disabilities (DM-ID) is a comprehensive clinical guide for health care professionals that offers diagnostic criteria for mental illness adapted for patients who have intellectual disability. The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) is a questionnaire that caregivers can use to identify mental illness. These are two important resources for identifying mental illness in people with developmental disabilities. What makes dual diagnosis challenging, however, is accurately separating out “behaviors” attributable to developmental disability from symptoms of psychiatric illness.

Alicia is a 21 year old woman with Down Syndrome who has developed a habit of twirling her hair. This has escalated such that she has several bald spots. Parents are also concerned because Alicia is repeating phrases, talking to herself more, and ruminating about her boyfriend. Mother describes Alicia as having “looping thoughts” about whether Alicia’s boyfriend will come to visit on certain days of the week. A-B-C charting reveals that the hair twirling interferes with Alicia’s performance at work. Alicia’s physician reviews the DM-ID criteria for the diagnosis of anxiety disorders in persons with intellectual disability, and prescribes a medication for obsessive compulsive disorder. Counseling is provided via the DDSO. At the follow-up visit 6 weeks later, Alicia’s mother states that all of the symptoms have “melted away”.

The vignettes listed above are examples for each of the diagnosis categories included on the Comprehensive Evaluation Table on page 2. This table is designed to help caregivers and health care providers to think carefully about all possible causes for escalating behaviors. It is important to keep in mind that behaviors can be multifactorial in origin. Systematic consideration of each of the categories listed on the table, and frequent reassessment with A-B-C charting is key to this iterative approach.
Overview of Functional Behavioral Analysis

Adapted from the Center for Effective Collaboration and Practice: [http://cecp.air.org/fba](http://cecp.air.org/fba)

**Functional Behavior Assessment (FBA)** is a tool for identifying the cause of a behavior. FBA uses a systematic approach called A-B-C- charting. A-B-C stands for antecedent-behavior-consequence. A-B-C charting begins with the identification of a **target behavior**. This is typically a behavior identified as inappropriate, harmful, or maladaptive and in need of modification. The next step is to look closely at, and systematically keep track of, the **antecedents** of the behavior (what happened just prior to the display of the target behavior) as well as the **consequences** of the behavior (what happens right after a behavior). The consequence is often a powerful reinforcement. Functional Behavioral Assessment is done over several days and in multiple settings, in order to identify a pattern. A-B-C charting can answer questions such as:

- What motivates a person to display a specific behavior?
- Does s/he want someone’s attention, for example, a caregiver or the teacher?
- Does s/he want to get away from something or someone, for example, an academic demand or a bothersome peer?
- Does s/he want a tangible object, for example, food or a toy?
- Does s/he do it because it feels good or is self-reinforcing, for example, rocking or hand flapping?

The functional assessment of behavior provides hypotheses or informed guesses about the relationships between specific environmental events and behaviors. The FBA is used to identify the type and source of reinforcement for challenging behaviors as the basis for intervention efforts designed to decrease the occurrence of these behaviors or to replace them with more positive, prosocial ones. Both positive and negative behaviors can be reinforced.

The FBA technique allows a teacher, psychologist, physician, or parent to hypothesize on the motivation of the behavior. For example, if a calm child is put into a car seat and starts to scream, what is the caregiver’s response? If the caregiver removes the child and the child calms down, then the hypothesis can be made that the child wanted to “escape” the car seat and used the screaming behavior to convey that. If the caregiver leaves the child in the car seat, but is able to calm the child with talking, then the hypothesis is that the child wanted the caregiver’s attention and used screaming to get it. The same target behavior, screaming, can come from very different motivations. In the case of escape, the caregiver needs to look closely at the comfort of the car seat or perhaps fear as an explanation. If the child simply wants the caregiver’s attention, then helping the child to get attention in a more appropriate way might be the intervention. The FBA is an excellent tool to help figure this out.

**FBA** utilizes direct observation of behavior under naturally occurring conditions. The ABC (antecedent-behavior-consequence) approach described above is used to record observed target behavior and any events that immediately precede and follow the target behavior across multiple settings and over several days.

The “**Indirect**” FBA is a method that uses structured interviews, checklists, rating scales, or questionnaires to obtain information from persons who are familiar with the person exhibiting the behavior. The intent is to identify possible conditions or events in the natural environment that correlate with the problem behavior. It is called “indirect” because it does not involve direct observation of the behavior. The Indirect FBA is based on others’ recollections of the behavior. There are pros and cons to using an Indirect FBA rather than a traditional FBA and A-B-C charts. The positive aspect is that it can provide useful information and can contribute to the hypothesis. The negative aspect of the indirect technique is that informants are not always able to recall events with accuracy. Memory can fade with time.
**INTERVENTIONS BASED ON AN FUNCTIONAL BEHAVIORAL ANALYSIS**

Understanding the function of a behavior is critical to changing it. A thorough review of the information gathered allows for a systematic analysis of the behavior. A treatment plan based on how environmental factors influence behavior can then be developed.

*The function of a given behavior typically falls under one of four motivations:*

- to gain attention
- to escape a demand
- to obtain a tangible reward
- for self stimulation

Some of the interventions that result from this type of approach involve teaching specific communication skills to replace the problem behavior, as well as specifically managing the setting and/or the consequences for a behavior. A whole curriculum referred to as *Positive Approaches to Behavior Change* has evolved out of this type of analysis (Carr et. al. 2002). This approach differs from pathology-based models for evaluating and treating behaviors because the emphasis is on prevention and the focus is on personal competence, self-determination, and the participation of all stakeholders.

The **Center for Effective Collaboration and Practice** (CECP) has an excellent website, [http://cecp.air.org/fba/](http://cecp.air.org/fba/), that offers a complete set of instructions for doing a Functional Behavioral Analysis with interview forms that can be used to do an Indirect FBA. This website also has instructions for creating positive behavior plans and supports.
WHERE
Can I Go to Learn More?

This section lists state and national web resources relevant to dual diagnosis. These websites are organized by topics that correspond to the table on page 2: Comprehensive Evaluation and Treatment of Behaviors in People with Developmental Disabilities.

PHYSICAL HEALTH

NYS Office for People with Developmental Disabilities:  http://www.opwdd.ny.gov/
The New York State Office for People with Developmental Disabilities (OPWDD) provides services and supports for people with developmental disabilities across the lifespan.

NYACTS:  http://www.nyacts.org/
NYACTS is an initiative of the New York State Office for People with Developmental Disabilities (OPWDD) for adults and children on the autism spectrum. The NYACTS website is a portal to help families access services and supports for people with autism throughout the lifespan.

American Academy of Cerebral Palsy and Developmental Medicine:  http://www.aacpdm.org/
Provide multidisciplinary scientific education for health professionals and promote excellence in research and services for the benefit of people with cerebral palsy and childhood-onset disabilities.

American Academy of Developmental Medicine and Dentistry:  http://www.aadmd.org/
The American Academy of Developmental Medicine and Dentistry (AADMD) was organized in 2002 to provide a forum for healthcare professionals who provide clinical care to people with neurodevelopmental disorders and intellectual disabilities (ND/ID). The mission of the AADMD is to improve the overall health of individuals with ND/ID through patient care, teaching, research and advocacy.

The Arc is the premier provider of supports and services for people with intellectual and developmental disabilities and has a demonstrable record of success in achieving the outcomes people want for their lives. The Arc believe that people with intellectual and developmental disabilities are entitled to the rights afforded every American and that they demand to be included and participate as full members of the community. Our chapters are vital in providing the supports and services crucial to achieving these goals.

Autism Speaks:  http://www.autismspeaks.org/index.php
Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Since then, Autism Speaks has grown into the nation’s largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.
**United Cerebral Palsy:** [http://www.ucp.org/](http://www.ucp.org/)
One of the largest health nonprofits in the U.S., the UCP mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network. This includes approximately 100 local service providers, known as “affiliates,” reaching more than 176,000 individuals and their families daily in the U.S., Australia, Canada, and the U.K. (Scotland).

**LEARNED BEHAVIOR**

**Center for Effective Collaboration and Practice:** [http://cecp.air.org/fba](http://cecp.air.org/fba)
The Center for Effective Collaboration and Practice (CECP) offers a complete set of instructions for doing a Functional Behavioral Analysis as well as interview forms that can be used to do an Indirect FBA. This website also has instructions for creating positive behavior plans and supports.

**Capacity Works:** [http://www.capacityworks.com/about.html](http://www.capacityworks.com/about.html)
Through the years, Beth Mount's artwork, publications, and posters have served to inspire us all to realize that every person with a disability is a valuable and productive member of community life. The impact of Beth’s 30 year body of work has been extensive and is known throughout the world. Her work has been instrumental in helping people to find meaning in supporting people with disabilities to build their lives.

**SENSORY ISSUES**

**National Consortium on Deaf-Blindness:** [http://nationaldb.org/](http://nationaldb.org/)
Excellent resource for information on communication approaches that can be used with people who have sensory impairments and/or who have multiple disabilities.

**Sensory Processing Disorder Foundation:** [http://www.sinetwork.org/](http://www.sinetwork.org/)
SPD Foundation offers an abundance of services and programs for professionals, parents, and anyone interested in knowing more about the sensory challenges that affect children academically, socially, and/or in their emotional development.

**CHANGE IN ROUTINE**

**Gray Center Social Stories:** [http://thegraycenter.org/social-stories](http://thegraycenter.org/social-stories)

A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. Half of all Social Stories™ developed should affirm something that an individual does well. Although the goal of a Story™ should never be to change the individual’s behavior, that individual’s improved understanding of events and expectations may lead to more effective responses.

**INADEQUATE COMMUNICATION**

**Communication Matrix:** [http://www.communicationmatrix.org/](http://www.communicationmatrix.org/)
An easy to use assessment instrument designed for individuals of all ages who function at the earliest stages of communication and who use any form of communication.

**National Consortium on Deaf-Blindness:** [http://nationaldb.org/](http://nationaldb.org/)
Excellent resource for information on communication approaches that can be used with people who have sensory impairments and/or who have multiple disabilities.
CAREGIVER STRESS

Parent to Parent of New York State:  http://www.parenttoparentnys.org/
Families of individuals with special needs, and the professionals who serve them, can meet and share information.

New York State Council of Children and Families:  http://www.ccf.state.ny.us/Initiatives/CCSIHome.htm
Coordinated Children’s Services Initiative: CCSI serves as a mechanism to make certain that multiply-diagnosed children receive the necessary services and supports that will allow them to remain in their homes, schools, and communities. CCSI ensures the coordinated delivery of services through a three tier interagency structure that addresses service barriers at the provider-, county-, and state-levels.

QUALITY OF LIFE

Capacity Works:  http://www.capacityworks2.com
Through the years, Beth Mount’s artwork, publications, and posters have served to inspire us all to realize that every person with a disability is a valuable and productive member of community life. The impact of Beth’s 30 year body of work has been extensive and is known throughout the world. Her work has been instrumental in helping people to find meaning in supporting people with disabilities to build their lives.

NYS Inclusive Recreation Resource Center:  http://www.nysirrc.org/about.html
The mission of the NYS Inclusive Recreation Resource Center is to promote and sustain participation by people with disabilities in inclusive recreation activities and resources throughout the state.

Independent Living Centers:  http://www.acces.nysed.gov/vr/lfn/ilc/about.htm
Independent Living Centers (ILCs) provide an array of services that assist New Yorkers with disabilities to live integrated and self-directed lives. ILCs assist with living learning and earning remove barriers to full participation in to the local community and beyond. ILCs are private, not-for-profit organizations, governed by a majority of people with disabilities and staffed primarily by people with disabilities. ILCs are resource centers that do not run residential programs or operate places where people live. The philosophy of independent living is to maximize opportunities for choices and growth through peer driven supports and self-help. ILCs are the voice of people with disabilities and the disability rights movement in local communities across New York State. Peer counseling is available at most Independent Living Centers.

Self Advocacy Association of New York State:  http://www.sanys.org/
SANYS is a grassroots network for people with developmental disabilities that has regional chapters throughout New York State.

MENTAL HEALTH

Textbook of Diagnosis of Mental Disorders in People with Intellectual Disability (DM-ID):  http://www.dmid.org/
The National Association for the Dually Diagnosed (NADD), in association with the American Psychiatric Association (APA), developed a Manual that is designed to be an adaptation of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IV-TR). The title of this Manual is the Diagnostic Manual — Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability. Grounded in evidence based methods and supported by the expert-consensus model, Diagnostic Manual — Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability offers a broad examination of the topic, including a description of each disorder, a summary of the DSM-IV-TR diagnostic criteria, a review of the literature and research and an evaluation of the strength of evidence supporting the literature conclusions, a discussion of the etiology and pathogenesis of the disorders, and adaptations of the diagnostic criteria for the ID population. A shorter volume, Diagnostic Manual — Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability has been abridged for clinical usefulness. It focuses on issues related to diagnosis in people with ID, the limitations in applying DSM-IV-TR criteria to people with ID, and adaptation of the diagnostic criteria.

NADD developmental disability and mental health needs:  http://www.thenadd.org/
NADD is the leading North American expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to persons with intellectual or developmental disabilities.
CHALLENGING BEHAVIORS

The New York State Office of Mental Health operates psychiatric centers across the State, and also regulates, certifies and oversees more than 2,500 programs, which are operated by local governments and nonprofit agencies. These programs include various inpatient and outpatient programs, emergency, community support, residential and family care programs.

NYACTS: http://www.nyacts.org/
NYACTS is an initiative of the New York State Office for People with Developmental Disabilities (OPWDD) for adults and children on the autism spectrum. The NYACTS website is a portal to help families access services and supports for people with autism throughout the lifespan.

The New York State Office of Children and Family Services (OCFS) provides a system of family support, juvenile justice, child care and child welfare services that promote the safety and well-being of children and adults. OCFS is responsible for programs involving foster care, adoption, child protective services, preventative services for children and families, services for pregnant adolescents, and protective programs for vulnerable adults. OCFS is also responsible for the functions performed by the State Commission for the Blind and Visually Handicapped and coordinates state government response to the needs of the Native Americans on reservations and in communities.

A statewide coalition of people who use and/or provide recovery oriented community based mental services. They value difference and promote cultural competence in all aspects of their work. NYAPRS is dedicated to improving services and social conditions for people with psychiatric disabilities or diagnoses, and those with trauma-related conditions by promoting their recovery, rehabilitation and rights so that all people can participate freely in the opportunities of society.

NYS Chapter of National Alliance on Mental Illness: http://www.naminys.org/
NAMI-NYS is the state organization of the National Alliance on Mental Illness, the nation's largest grassroots organization for people with mental illness and their families. NAMI-NYS provides support to family and friends of individuals with mental illness and persons living with mental illnesses through more than 50 affiliates statewide. The website for the National Alliance on Mental Illness is: http://www.nami.org

The New York State Developmental Disabilities Planning Council is a Federally-funded New York State Agency working under the direction of the Governor’s Office. The DDPC is responsible for developing new ways to improve the delivery of services and supports to New Yorkers with developmental disabilities and their families. The Council focuses on community involvement, employment, recreation and housing issues faced by New Yorkers with developmental disabilities and their families.

MHANYS and its affiliate network work to promote mental health and recovery, encourage empowerment in mental health service recipients, eliminate discrimination, raise public awareness with education, and advocate for equality and opportunity for all. MHANYS works to ensure available and accessible mental health services for all New Yorkers. Website for the national Mental Health Association: http://www.nmha.org

The mission of the NYS Rehabilitation Association is to provide leadership and advocacy on multiple matters of public policy on behalf of community rehabilitation providers, and to work with individuals with differing abilities and other consumers to improve and enhance rehabilitation and educational services throughout the State; Inform, educate, and support NYSRA members in their efforts to offer a diverse spectrum of services and employment opportunities to consumers; and Support and promote policy and other initiatives that will help integrate and mainstream people with differing abilities into the community.
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In addition to this guidebook, the Institute also offers 10 Continuing Education Modules, 6 Lesson Plans and a series of 30 video vignettes with moderator guide on health care transition for youth with developmental disabilities. The Healthy Transitions website, curriculum and tools are owned by the New York State Developmental Disabilities Planning Council. All of our materials may be reproduced and distributed for educational purposes.

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