Effective Strategies Checklist
Children and Youth with Developmental Disorders and Challenging Behavior

Children and youth who have intellectual disabilities or developmental disorders are at elevated risk for co-occurring psychiatric or behavioral problems. These individuals pose a serious challenge for administrators, program directors and clinicians, especially when they present with aggressive or disruptive behaviors. They are often the most difficult and costly to serve. Across the country, their families report relentless stress, partly because it is very difficult to obtain the help they need. This paper provides resources and strategies that have proven to be effective and which have lowered costs, as well as risks for out of home placement, including juvenile justice and child welfare.

REVIEW CRITICAL INFORMATION FOR ADMINISTRATORS AND CLINICIANS

☐ This is an extremely heterogeneous group of individuals with differing strengths and needs. There is no one-size-fits-all approach.

☐ The prevalence of psychiatric disorders is much higher than generally recognized among children and youth with intellectual disability (ID), estimated to be between 30-50% (Einfeld, et. al, 2011). The diagnoses may reflect “classical” psychiatric disorders as well as severe behaviors in response to stress in individuals who lack functional communication. That said, people with developmental disorders are subject to the full range of psychiatric disorders. Co-occurring conditions (for example, anxiety and attention-deficit/hyperactivity disorder) are very common in children with autism spectrum disorders (Simonoff, et. al, 2008) and also among children with other developmental disorders such as cerebral palsy and epilepsy.

☐ Psychiatric disorders may present very differently in people with developmental disabilities than in typically developing individuals, particularly if they cannot describe their inner state. An increase in non-specific behaviors such as hitting or screaming may signal distress due to diverse sources including physical pain, anxiety, frustration trauma or grief.

☐ The stress for parents may be unrelenting. Many parents lose their jobs because of the all-consuming demands of caring for a child who is violent, disruptive or unstable. Parents commonly report feeling blamed, exhausted and isolated. Many develop stress-related illnesses. Sometimes they are frightened for the safety of other family members.

☐ Parents describe long and painful searches for appropriate assessments, medical evaluations or treatment, which are commonly unavailable or inadequate. They may be turned away from one public agency after another because their children have the “wrong” diagnosis or the wrong IQ (either too high or too low) or they have the “wrong” insurance. Fragmented services commonly result in multiple coordinators and separate plans in each system.

☐ Effective family supports are unavailable or hard to access in many communities, including respite care and assistance for couples and siblings.
A comprehensive interdisciplinary evaluation is essential and requires professionals with specific expertise in co-occurring disorders.

Systematic crisis prevention planning and implementation of preventative environmental and behavioral supports are key to reducing violent or dysregulated behavior, along with training and supports for families and school personnel.

Predictable developmental milestones may trigger disruption or grief for individuals with intellectual or developmental disability (IDD), such as when siblings leave home, a caregiver leaves, etc.

Crises are commonly precipitated by adverse drug reactions. Use of multiple medications is common for individuals with developmental disabilities, even young children. Appropriate environmental and psychotherapeutic strategies need to be employed instead of or in addition to medication.

Crises are often driven by unidentified medical problems, which may go undetected without a thorough evaluation.

Violent behavior often reflects a mismatch between environmental demands and the individual’s interests, strengths and skills. Crises may relate to inadequate in-home supports and lack of systematic approaches to preventing violent outbursts. A poorly developed Individualized Education Plan may not sufficiently address preventative supports or building of skills to replace and reduce challenging behaviors.

Many individuals with developmental disabilities experience maltreatment, including physical abuse, sexual abuse or neglect. History of traumatic exposure must be assessed. Trauma-informed systems and evidence-based practices should be employed, including trauma-specific psychotherapy adapted for individuals with disabilities.

Effective and respectful services for individuals with complex needs require person-centered, culturally competent and family-driven planning. Sometimes people fail to ask individuals with disabilities about their experience and take what they say to heart. Ongoing training is required to assure that these values become reality.

Sometimes the most important intervention is to assure that an individual with a developmental disorder has meaningful days and meaningful relationships, with a feeling of belonging (Pitonyak, 2010).

ADD NEEDED SERVICE COMPONENTS:

A multidisciplinary clinical team of experts in co-occurring developmental and psychiatric disorders is critical. The assessment and treatment of this population requires a different skill set than needed for the general population. Expert assessment is needed to identify the reasons for the aggressive or disruptive behavior. In communities where this expertise is not available, consultation can be arranged in various ways to support and train local providers (including webinars and telephone consultation).

Intensive care coordination is critical as well to provide linkages among agencies, integrated care planning, assistance to all family members and crisis prevention planning and support. The Center for START Services at the University of New Hampshire has pioneered...
a an approach expressly designed for individuals with co-occurring psychiatric and developmental disorders (www.centerforstartservices.com) Coordinators trained in High Fidelity Wraparound Coordination (see www.nwi.pdx.edu) will have many needed skills but may require additional training to work with this population effectively.

- **Planned therapeutic respite care** provides intensive diagnostic and intervention services and parent training in a (fun) weekend retreat. At the end of the weekend, staff members train the parents on using techniques they found effective. These services are far less expensive than inpatient care and more effective. (see http://www.centerforstartservices.com/default.aspx).

- **Mobile crisis outreach and emergency respite care** are needed for psychiatric hospital diversion on a full-time basis (nights and weekends included).

- **Crisis prevention planning** is central. Families need emergency supports to call in during a crisis, and also training in preventing and de-escalating a crisis.

- **Specialized inpatient beds with staff who understand IDD and ASD** will always be needed to sort out diagnoses, medical issues and medication.

- **Positive behavioral support** strategies need to be implemented with fidelity. This does not always occur, especially in school settings. For example, teachers need support to implement frequent and consistent positive feedback and tailor expectations that are in line with the student’s capacities.

- **Capacity to systematically teach skills** needed to prevent the behavior.

- **Psychotherapy** can be very helpful for many individuals with intellectual disability benefit from therapy, and it is often overlooked as an option. An adapted form of Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) may be helpful for some, as may various approaches that support self-regulation, such as Dialectical Behavior Therapy, which has also been adapted for this populations (DBT-SP) (Charlton and Dykstra, 2011).

- **Primary care and dental providers** who acquire the skills for success with this population

- **Family Therapy** to ensure all needs of family members are addressed

- **Supports for siblings** to ensure each individual’s needs addressed in support of person with the co-occurring disorder.

- **Occupational Therapy** as an important medical clinical service to address sensory regulation and teach calming techniques in handling activities of daily life.

- **Speech and language consultation and therapy**, including alternative augmentatives communication, is critical for individuals who do not have a functional communication system or if a language disorder is present, as in those with autism.

- **Social Supports from community agencies** for housing, transportation, vocational rehabilitation, long-term planning.
Promising Practices are practices shown to be effective through research detailed in Davis, Jivanjee, & Koroloff, 2010) Paving the way: Meeting transition needs of young people with developmental disabilities and serious mental health conditions (available online at http://www.rtc.pdx.edu/PDF/pbPavingTheWayMonograph.pdf)

Program Evaluation guides collection and analysis of service data on costs and outcomes.

BUILD A SENSE OF URGENCY FOR CHANGE

- Conduct focus groups with parents, foster parents and providers from mental health, special education, developmental disabilities and other systems to better understand the local issues and to build a shared understanding of the urgency of needs. Assure that all ethnic and language groups are well represented. Identify service gaps, recommendations, barriers to integrated services.

- Set up an interagency planning and advisory committee including several family members and youth representatives. Consider carefully key stakeholders who need to be represented.

- Obtain existing data at state and local levels to understand baseline rates, services used, baseline costs, service gaps, hospitalization, juvenile justice, child welfare, homelessness.

- Identify local resources. Study gaps in service, additional supports identified as needed, and create a list of available resources and services.

- Set up cross-system case conference and present (de-identified) individuals who are “high flyers,” who require a lot of expensive services from several systems but whose need are not well addressed.

- Develop a call to action for the state or locality.

STRENGTHEN INFRASTRUCTURE AND WORKFORCE READINESS

- Locate or develop a multidisciplinary clinical diagnostic and consultation team of specialists in co-occurring disorders, including a child psychiatrist, developmental pediatrician, psychologist, behavior specialist, occupational therapist, physical therapist, and speech and language pathologist. If local resources are not available, focus on infusing expertise among local providers through consultation and training (resources provided in this document) rather than developing parallel services.

- Use the interagency planning and advisory body that includes community agencies and family stakeholders to monitor the implementation and management of the Call to Action, with primary attention on maintaining services integration.

- Set up cross-system training for providers and other stakeholders.

- Maximize use of existing data systems to support quality improvement.

- Closely review the values and principles of a formal System of Care (See Stroul, Blau, & Friedman, 2010; Pires, 2010), strategic frameworks of services and supports organized into a coordinated network, supported by core values, and which are family-driven, youth
guided, home and community based, and culturally and linguistically competent. Assure best practices are fully incorporated into community services.

- **Develop service linkages** using a community START team ([www.centerforstartservices.com](http://www.centerforstartservices.com)) or System of Care approach with High Fidelity Wraparound (See Stroul, Blau, & Friedman, 2010; Pires, 2010).

- **Assure** that there is a single plan of care for each family.

- **Identify a care coordinator** who has experience working with youth who have co-occurring developmental and psychiatric disorders and provide training in system linkages. Ideally, this would be a START Team Coordinator or High Fidelity Wraparound Coordinator (resources provided).

- **Crisis prevention planning is central.** Identify classes of individuals likely to be at high risk (prior history of violence or disruptive behavior, multiple medications, unstable home or school situation, prior trauma experiences, etc.) and focus on prevention of crises.

**IDENTIFY FINANCING STRATEGIES**

- **Financing strategies to identify and support additional children and youth** may be found at [http://www.hdwg.org/catalyst/cover-more-kids](http://www.hdwg.org/catalyst/cover-more-kids) (resources from the Catalyst Center)

- **Strategies to close benefit gaps**: (resources from the Catalyst Center) [http://www.hdwg.org/catalyst/close-benefit-gaps/](http://www.hdwg.org/catalyst/close-benefit-gaps/)

- **CMS Waiver and State Plan Options to consider**

  - The **1915 (i) State Plan Amendment** is set up to help states flexibly address the needs of one or more specific populations for home and community based service (HCBS) under Medicaid [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html)

  - **1915 (c) Home and Community-based Waivers** make it possible for states to use Medicaid funds usually available for long-term residential care for services in the home and community instead. [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html)

  - **Health Homes**: Under the Affordable Care Act, enhanced Medicaid funds are available for two years to encourage establishment of well-coordinated services and care coordination for people with chronic conditions, including those with co-occurring developmental and psychiatric disorders. These services are provided through a network of providers, health plans and community-based organizations. [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Health-Homes/Health-Homes.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Health-Homes/Health-Homes.html)
• **Money Follows the Person**: Children or youth in qualifying residential facilities (including Intermediate Care Facilities) for at least 90 days may be eligible for community-based services with enhanced federal funding if their state participates in CMS’s Medicaid-based Money Follows the Person (MFP) demonstration program. This provides up to 6 months of pre-discharge planning funds plus 365 days of Home and Community Based Services. To see if your state participates and if children and youth are included, go to: [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html).

□ Important Federal Guidance: Informational Bulletins on the CMS website:


**USE DATA TO DRIVE SERVICES AND DOCUMENT COST-BENEFITS**

□ Data collection and reporting need to be ongoing in order to sustain support and change services as needed

□ Data needs to include
  - Careful analysis of costs compared to typical services
  - Satisfaction of the youth and family
  - Objective assessment of progress toward goals using standardized tools

□ Systematic epidemiological, assessment and treatment study is needed for this population.

**RESOURCES**


NADD, An Association for Individuals with Developmental Disabilities and Mental Health Needs: www.thenadd.org

National Child Traumatic Stress Network www.nctsn.org (developing resources for prevention and response to trauma for this population)

The Center for START Services, University of New Hampshire, a nationwide research-based, systems-linkage program that provides person-centered supports and clinical treatment, as well as training for professionals http://www.centerforstartservices.com/default.aspx

The Catalyst Center – user-friendly resources on financing options http://www.hdhwg.org/catalyst/

Association of University Centers on Developmental Disabilities, www.AUCD.org

Federation of Families for Children’s Mental Health: www.ffcmh.org

Parent Centers in each state: http://www.taalliance.org/index.asp

National TA Center for Children’s Mental Health (resources for this population and Systems of Care) http://gucchdtacenter.georgetown.edu/

ADDITIONAL SOURCES


Charlton, Margaret, Dykstra, Eric J, (2011),"Dialectical behavior therapy for special populations: treatment with adolescents and their caregivers", Advances in Mental Health and Intellectual Disabilities, Vol. 5 Iss: 5 pp. 6 -14 Permanent link to this document: http://dx.doi.org/10.1108/20441281111180619


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Prepared by Diane M. Jacobstein, PhD, (jacobstd@georgetown.edu), Georgetown National Technical Assistance Center for Children's Mental Health, with funding from the Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services.

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