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 young people pose a serious challenge for administrators, program directors and clinicians, especially when they present with aggressive or disruptive behaviors. When appropriate community services have not been organized, these youth can be among 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 improved outcomes and lowered costs, while diminishing risk for institutional placements, referrals to juvenile justice and child welfare.

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, but effective interventions have been developed.

☐ **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 behavioral responses 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, Leyfer, et. al., 2006) and also among children with other developmental disorders such as cerebral palsy and epilepsy.

☐ **The stakes are high**, since lack of effective treatment places these children and youth at elevated risk for out-of-home placement in child welfare, juvenile justice, institutions and eventual homelessness.

☐ **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.

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☐ **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.**

☐ **Psychiatric disorders may present very differently in people with developmental disabilities than in typically developing individuals**, particularly if they cannot describe their inner states. 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.

☐ **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.

☐ **People with disabilities and challenging behavior are exposed to serious human rights violations.** These include unnecessarily restrictive placements, exclusion from services based on the disability, preventable seclusion and restraint, custody relinquishment as a requirement to obtain services and sometimes even invasive surgical procedures undertaken in a misguided effort to curtail behavior that could be better addressed through behavioral treatment.

☐ **Services and supports that are effective for typically developing children and their families can be very helpful for these children as well**, including trauma treatment, psychotherapy, a Systems of Care approach with cross-systems integration of services and intensive care coordination.

☐ **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 experiences 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, as well as a feeling of belonging** (Pitonyak, 2010).

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 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 in a camp-like 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 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 during a crisis, and also training in preventing and de-escalating challenging behavior.

- ☐ **Specialized inpatient beds with staff who understand IDD and ASD** are needed for short-term stays 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, teach replacement behaviors and tailor expectations that are in line with the student's capacities.

- ☐ **Psychotherapy** can be very helpful. 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) and mindfulness-based approaches.

- ☐ **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** are very important.

- ☐ **Occupational therapy** as an important medical clinical service to address sensory regulation and teach calming techniques for handling activities of daily living.

- ☐ **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 www.rtc.pdx.edu/PDF/pbPavingTheWay Monograph.pdf).

☐ **Periodic ongoing guidance from a representative advisory council of parents** is very important for a successful program. Parents should be involved at all levels of planning, research and programming.

☐ **Adequate provision for evaluation** is needed to guide collection and analysis of service data on costs and outcomes.

How to 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.

☐ **Identify local resources.** Study gaps in service, additional supports needed, and create a list of available resources and services.

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

☐ **Set up cross-system case conferences** to support interagency planning. Present de-identified individuals who require many expensive services from several systems but whose need are not well addressed.

☐ **Develop a call to action** for the state or locality. Parent advocates are often the most effective in driving needed changes.

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). This is a strategic framework of services and supports organized into a coordinated network and supported by core

values, which is 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) 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 with specialized training.

☐ **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 www.hdwg.org/catalyst/cover-more-kids (resources from the Catalyst Center)

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

☐ **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. 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. 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. 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: 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:**

• Guidance from CMS and SAMHSA jointly on Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions. www.medicaid.gov/federal-policy-guidance/downloads/CIB-05-07-2013.pdf

• Prevention and Early Identification of Mental Health and Substance Use Conditions—Guidance from CMS: www.medicaid.gov/federal-policy-guidance/downloads/CIB-03-27-2013.pdf

☐ Letter to State Medicaid Directors from the Department of Health and Human Services on trauma and how to set up and pay for trauma treatment: www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-07-11.pdf

Using Data to Drive Services and Document Cost-Benefits

☐ Data collection needs to be thoughtfully planned to provide ongoing feedback for quality improvement

☐ Data is critical for sustained funding support

☐ Data needs to include

• Careful analysis of costs and service utilization

• Satisfaction of the youth and family

• Objective assessment of progress toward goals using standardized tools

☐ Systematic epidemiological, assessment and treatment research is needed for this population.

Resources

• **Families' Experiences:** *Listening and Learning from Families Caring for a Child with Co-occurring Disorders: Mental Health, Substance Abuse, Developmental Disabilities*, Maryland Coalition of Families for Children's Mental Health, available at www.mdcoalition.org.

• **Guide to Best Practices and Promising Practices:** Davis, M., Jivanjee, P., & Koroloff, N. (2010). *Paving the way: Meeting transition needs of young people with developmental disabilities and serious mental health conditions.* www.rtc.pdx.edu/PDF/pbPavingTheWayMonograph.pdf

• **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: www.centerforstartservices.com/default.aspx

• **The Catalyst Center**—user-friendly resources on financing options: www.hdwg.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: 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
- Baker, D., & Blumberg, R. (Eds.). (2013). *Mental Health and Wellness Supports for Children and Youth with Intellectual Disabilities.* Kingston: NADD Press. Describes individual, family and school-based treatment and positive supports.
- Fletcher, R. (2011). *Psychotherapy for individuals with intellectual disability.* Kingston, NY, NADD Press. Describes individual, family and group approaches for adults and children.

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