NCTSN The National Child Traumatic Stress Network

Hogg Foundation for Mental Health
ADVANCING RECOVERY AND WELLNESS IN TEXAS

The Road to Recovery:
Supporting Children with IDD Who Have Experienced Trauma

Supplemental Materials

November 2015

Contents

Brief Papers on Trauma & IDD 3

The Ecological Model (Urie Bronfenbrenner).. 5

Erikson's Theory of Psychosocial Development 6

The Risk & Protective Factors Model 8

Federal Definition of Intellectual & Developmental Disabilities 9

Disabilities 10

Individuals with Disabilities Act (IDEA) 14

What is child traumatic stress? 16

The 12 Core Concepts for Understanding Traumatic Stress Responses in Children & Families 19

DSM-5 Criteria for Posttraumatic Stress Disorder (PTSD) 25

Resources for Gentle Teaching, Positive Behaviors Support, & Positive Identity Development 26

NCTSN Sites 27

Resources for Families 28

Developmental Surveillance & Screening 30

Recovery Plans & Person-Centered Planning Tools 31

Empirically Supported Trauma-Informed Treatment & Promising Practices 33

Effective Strategies Checklist 37

Day 1, Module 1, Slides 12-13

Brief Papers on Trauma & IDD

These Briefs were written by the NCTSN Trauma and IDD Expert Panel and can be found on the NCTSN Learning Center for Child and Adolescent Trauma.

Adams, R. (2014). *An Unseen Population: IDD and Interventions for Young Children*. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Adams brief discusses supportive intervention for parents of young children with IDD. Dr. Adams describes how the application of the EBD Framework to the context of traumatic stress exposure can alter the trajectory for overall health.

Adams, R. (2014). *Un Unseen Population: IDD and Trauma, Vulnerabilities among Children with IDD in Abusive or Foster Homes*. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Adams describes removing young children from their homes and the adverse effect that it may have on children with IDD. This brief also offers a look at some of the challenges that exist when working with children with IDD who have been removed from their biological homes.

Padura-Álvarez, I. (2014). *An Unseen Population: IDD and Working with Youth in Educational Settings.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Ms. Padura-Álvarez offers a look into what mental health providers can do when working in educational settings with children with IDD.

Bodan, R. (2014). *An Unseen Population: IDD and Trauma, Medical Trauma in Children with Rare Genetic Disorders.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Ms. Bodan offers a first person glance into a parent's journey of having a child diagnosed with a rare genetic disorder while navigating a complicated system.

Garrison-Tate, J. (2014). *An Unseen Population: IDD and Challenges that Parents Face—A Dad's Perspective.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Mr. Garrison-Tate describes his personal experience with supporting individuals with intellectual disabilities and mental illness, including his own daughter. This brief offers insight into the challenges a parent faces when trying to support his family.

Harvey, K. (2014). *An Unseen Population: IDD and Exposure to Drugs In-Utero.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Ms. Harvey offers a look at the trauma of being exposed in-utero to crack-cocaine or a combination of crack-cocaine and alcohol.

Horton, C. (2014). *An Unseen Population: IDD and the Focus on Managing Behavior—The Need for Change.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Ms. Horton describes how children with IDD exhibiting challenging behaviors often do not receive state-of-the-art mental health treatment; instead there is a focus on managing behavior with compliance as the primary goal.

Jacobstein, D. (2014). *An Unseen Population: IDD and Policy Considerations*. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Jacobstein discusses how to start a state-wide or community-wide conversation using a strategic planning process, including policies that promote prevention, address access and eligibility issues, identification of individuals who need support, treatment and crisis supports, and data collection for quality improvement.

Marrow, M. (2014). *An Unseen Population: IDD, Co-Occurring Disorders, and Service Delivery.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Marrow looks at the support and services individuals with intellectual and developmental disabilities have available and how co-occurring mental health disorders and/or trauma make access to services even more cumbersome.

Mooney, M. (2014). *An Unseen Population: IDD, Trauma, and Accurate Diagnosis.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Mooney presents information to support early and accurate diagnosis for children with IDD who have experienced trauma.

Rosenau, N. (2014). *An Unseen Population: IDD and the Challenges that Come With Recovery*. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Rosenau discusses the challenges children with IDD and their families face when trying to recover from trauma.

Tallant, B. (2014). *An Unseen Population: IDD and Trauma—Serving the Underserved.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Mr. Tallant provides background on how children and adults who have intellectual and developmental disabilities (IDD) are grossly underserved when it comes to the provision of mental health services, and in particular, the treatment of trauma.

Thompson, E. (2014). *An Unseen Population: IDD and Barriers for Families with Children Who Have Experienced Trauma.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Dr. Thompson describes the challenges and barriers to working with children with IDD who have experienced a trauma.

Vanderbilt, D. & Meneses, V. (2014). *An Unseen Population: IDD and Trauma, Pediatric Care Challenges Part 1 – Primary Care Perspectives.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Drs. Vanderbilt and Meneses discuss the role of primary care providers, medical trauma, and the challenges for screening for trauma in primary care settings with children with intellectual disabilities.

Vanderbilt, D. & Meneses, V. (2014). *An Unseen Population: IDD and Trauma, Pediatric Care Challenges Part 2 – Developmental-Behavioral Pediatric Perspectives.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.

> Drs. Vanderbilt and Meneses discuss clinical and community supports for children with IDD experiencing trauma, as well as integrating services.

Day 1, Module 1, Slide 24

The Ecological Model (Urie Bronfenbrenner)

- Bronfenbrenner identified four systems that each contains rules, norms, and roles that powerfully shape development. He called these the *microsystem*, the *mesosystem*, the *exosystem,* and the *macrosystem*.
- The **Microsystem** contains the immediate environments that the child is a part of (family, school, peer group, neighborhood, and childcare environments). It is the layer closest to the child and contains the structures with which the child has direct contact. At this level, relationships have impact in two directions – both away from the child and toward the child. For example, a child's parents may affect his beliefs and behaviour; however, the child also affects the behaviour and beliefs of the parent. Bronfenbrenner calls these *bi-directional influences,* and he shows how they occur among all levels of environment.
- The **Mesosystem** is comprised of connections between the child's immediate environments (i.e., a child's home and school). If a child is experiencing difficulties in school, it is likely that the family will be forced to have more interactions with the school's teachers and administrators, and those family-school interactions should have an effect on the child's functioning.
- The **Exosystem** contains the external environmental settings and other social systems that do not contain the developing child but indirectly affect development (e.g. a parent's workplace, neighborhood institutions, the media, the government, the economy etc.).
- Finally, the **Macrosystem** contains all of the various subsystems and the general beliefs and values of the culture, and is made up of written and unwritten principles that regulate everybody's behaviour. These principles- whether legal, economic, political, religious, or educational- endow individual life with meaning and value and control the nature and scope of the interactions between the various levels of the total social system.
- Bronfenbrenner later added the **Chronosystem,** which is made up of all the other levels. It refers to the way the each level has an influence on the one before and after it in a back and forth motion. It also pertains to the historical context of the time the child is reared in. For example, a great technological discovery, a war, or times of great economic trouble, can all have impact on the child's development.

Source: St. Rosemary Educational Institution. Growth and Development Theory: URIE BRONFENBRENNER (1917-2005). http://schoolworkhelper.net/growth-and-development-theory-urie-bronfenbrenner-1917-2005. Retrieved on: September 23, 2015.

Day 1, Module 1, Slide 25

Erikson's Theory of Psychosocial Development

Erik Erikson's Theory of Psychosocial Development has eight distinct stages. Erikson believed that each stage has a key conflict that must be resolved in order to develop a healthy personality and sense of self.

Trust vs. Mistrust. From ages birth to one year, children begin to learn the ability to trust others based upon the consistency of their caregiver(s). If trust develops successfully, the child gains confidence and security in the world around him and is able to feel secure even when threatened. Unsuccessful completion of this stage can result in an inability to trust, and therefore a sense of fear about the inconsistent world. It may result in anxiety, heightened insecurities, and an over feeling of mistrust in the world around them.

Autonomy vs. Shame & Doubt. Between the ages of one and three, children begin to assert their independence, by walking away from their mother, picking which toy to play with, and making choices about what they like to wear, to eat, etc. If children in this stage are encouraged and supported in their increased independence, they become more confident and secure in their own ability to survive in the world. If children are criticized, overly controlled, or not given the opportunity to assert themselves, they begin to feel inadequate in their ability to survive, and may then become overly dependent upon others, lack self-esteem, and feel a sense of shame or doubt in their own abilities.

Initiative vs. Guilt. Around age three and continuing to age six, children assert themselves more frequently. They begin to plan activities, make up games, and initiate activities with others. If given this opportunity, children develop a sense of initiative, and feel secure in their ability to lead others and make decisions. Conversely, if this tendency is squelched, either through criticism or control, children develop a sense of guilt. They may feel like a nuisance to others and will therefore remain followers, lacking in self-initiative.

Industry vs. Inferiority. From age six years to puberty, children begin to develop a sense of pride in their accomplishments. They initiate projects, see them through to completion, and feel good about what they have achieved. During this time, teachers play an increased role in the child's development. If children are encouraged and reinforced for their initiative, they begin to feel industrious and feel confident in their ability to achieve goals. If this initiative is not encouraged, if it is restricted by parents or teacher, then the child begins to feel inferior, doubting his own abilities and therefore may not reach his potential.

Identity vs. Role Confusion. During adolescence, the transition from childhood to adulthood is most important. Children are becoming more independent, and begin to look at the future in terms of career, relationships, families, housing, etc. During this period, they explore possibilities and begin to form their own identity based upon the outcome of their explorations. This sense of who they are can be hindered, which results in a sense of confusion ("I don't know what I want to be when I grow up") about themselves and their role in the world.

Intimacy vs. Isolation. Occurring in young adulthood, teens and young adults begin to share themselves more intimately with others. They explore relationships leading toward longer term commitments with someone other than a family member. Successful completion can lead to comfortable relationships and a sense of commitment, safety, and care within a relationship. Avoiding intimacy, fearing commitment and relationships can lead to isolation, loneliness, and sometimes depression.

Generativity vs. Stagnation. During middle adulthood, adults establish careers, settle down within a relationship, create their own families and develop a sense of being a part of the bigger picture. They give back to society through raising children, being productive at work, and becoming involved in community activities and organizations. By failing to achieve these objectives, they become stagnant and feel unproductive.

Ego Integrity vs. Despair. As adults grow older and become senior citizens, they tend to slow down their productivity, and explore life as a retired person. It is during this time that they contemplate their accomplishments and are able to develop integrity if they see themselves as leading a successful life. If they see their lives as unproductive, feel guilt about pasts, or feel that they did not accomplish their life goals, they become dissatisfied with life and develop despair, often leading to depression and hopelessness.

Source: Christopher L. Hefner. Chapter 3: Section 3: Erikson's Stages of Psychosocial Development. http://allpsych.com/psychology101/social_development/#.VZVabGD93gw AllPsych: Psych Central's Virtual Classroom, Last Update: 2015. Web. Retrieved on July 2, 2015.

Day 1, Module 1, Slide 26

The Risk & Protective Factors Model

- Life Course suggests that a complex interplay of biological, behavioral, psychological, and social protective and risk factors contribute to health outcomes across the span of a person's life.
- *Pathways or Trajectories* – Health pathways or trajectories are built – or diminished – over the lifespan. While individual trajectories vary, patterns can be predicted for populations and communities based on social, economic and environmental exposures and experiences. A life course does not reflect a series of discrete steps, but rather an integrated continuum of exposures, experiences and interactions.
- *Early Programming* – Early experiences can "program" an individual's future health and development. This includes prenatal programming (i.e. exposure in utero), as well as intergenerational programming (i.e., the health of the mother prior to conception) that impact the health of the baby and developing child. Adverse programming can either result directly in a disease or condition, or make an individual more vulnerable or susceptible to developing a disease or condition in the future.
- *Critical or Sensitive Periods* – While adverse events and exposures can have an impact at any point in a person's life course, the impact is greatest at specific critical or sensitive periods of development (e.g., during fetal development, in early childhood, during adolescence, etc.).
- *Cumulative Impact* – Cumulative experiences can also "program" an individual's future health and development. While individual episodes of stress may have minimal impact in an otherwise positive trajectory, the cumulative impact of multiple stresses over time may have a profound direct impact on health and development, as well as an indirect impact via associated behavioral or health service seeking changes. (This concept of cumulative impact is also referred to as "weathering"or "allostatic load".)
- *Risk and Protective Factors* – Throughout the lifespan, protective factors improve health and contribute to healthy development, while risk factors diminish health and make it more difficult to reach full developmental potential. Thus, pathways are changeable. Further, risk and protective factors are not limited to individual behavioral patterns or receipt of medical care and social services, but also include factors related to family, neighborhood, community, and social policy. Examples of protective factors include, among others: a nurturing family, a safe neighborhood, strong and positive relationships, economic security, access to quality primary care and other health services, and access to high quality schools and early care and education. Examples of risk factors include, among others: food insecurity, homelessness, living in poverty, unsafe neighborhoods, domestic violence, environmental pollution, inadequate education opportunities, racial discrimination, being born low birthweight, and lack of access to quality health services.

Source: Rethinking MCH: The Life Course Model as an Organizing Framework (HHS 2010)

Federal Definition of Intellectual & Developmental Disabilities

The term "developmental disability" means a severe, chronic disability of an individual that:

i. is attributable to a mental or physical impairment or combination of mental and physical impairments;
ii. is manifested before the individual attains age 22;
iii. is likely to continue indefinitely;
iv. results in substantial functional limitations in 3 or more of the following areas of major life activity:
    I. Self-care
    II. Receptive and expressive language
    III. Learning
    IV. Mobility
    V. Self-direction
    VI. Capacity for independent living
    VII. Economic self-sufficiency; and
v. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) INFANTS AND YOUNG CHILDREN - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Source: Administration on Intellectual and Developmental Disabilities (AIDD): Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)

Day 1, Module 2, Slide 38

Types of Disabilities

Developmental Milestones (http://www.abnormalchildpsychology.org/intellectual-disability)

Global Developmental Delay is diagnosed in infancy, when children fail to meet developmental milestones in an age-expected manner. These videos, produced by Eastern Idaho Regional Medical Center (EIRMC), show some critical developmental milestones shown by typically-developing infants. There are four videos available for viewing, broken down by age of the child.
Video 1 (https://www.youtube.com/watch?v=79NZUidN38Q) : 2-4 months old
Video 2 (https://www.youtube.com/watch?v=ilOPROa0BoI&list=PL63046B4A1BCC0596) : 4-6-months-old
Video 3 (https://www.youtube.com/watch?v=uQmqRIR2YxA&list=PL63046B4A1BCC0596&index=10) : 6-8-months-old
Video 4 (https://www.youtube.com/watch?v=KzEI8z7Q0RU&list=PL63046B4A1BCC0596) : 8-10-months-old

Genetic Disabilities

Down Syndrome (https://www.youtube.com/watch?v=XGZnO5Im5bM)

Down Syndrome (trisomy 21) is a common cause of Intellectual Disability in children. This video, produced by Baby Health Guru, provides an excellent introduction to the various causes of Down Syndrome and characteristics of children with this condition.

Fragile X Syndrome

Fragile X Syndrome is the most common inherited cause of Intellectual Disability in children. It is caused by a mutation on the X chromosome. Boys, who have only one X chromosome, are usually more affected than girls.

Prader-Willi Syndrome (https://www.youtube.com/watch?v=WYVtYfNrbUo)

Prader-Willi Syndrome (PWS) is a non-inherited genetic disorder usually characterized by mild Intellectual Disability, overeating and obesity, oppositional behavior toward adults, and obsessive-compulsive behavior. This excellent video, produced by the British National Health Service, shows a 12-year-old girl with PWS and her mother.

Angelman's Syndrome (https://www.youtube.com/watch?v=QwEq18u4r2Q)

Angelman's Syndrome is a genetically-based developmental disorder characterized by Intellectual Disability, speech impairment, happy demeanor, and unusual motor behavior. This brief video shows an eight-year-old boy with Angelman's Syndrome. It shows his unsteady gait, toe-walking, vocalizations, and happy facial expression.

Williams Syndrome (https://www.youtube.com/watch?v=sJFt0nDmdvM)

Williams Syndrome (WS) is a genetic disorder usually characterized by low intellectual functioning, unusual strengths in spoken language and sociability, hyperactivity, impulsivity, and inattention. This video, produced by the Williams Syndrome Association, features two parents discussing their experiences raising children with WS. It also shows several children with the condition.

Phenylketonuria (https://www.youtube.com/watch?v=1_lSwuidmQg)

This excellent video shows Molly, an eight-year-old girl with phenylketonuria (PKU). PKU is an inherited metabolic disorder than can cause severe Intellectual Disability. Molly discusses how she manages her condition by adhering to a strict diet and with the support of her family.

Neuromotor Disabilities

Cerebral Palsy (http://www.mychildwithoutlimits.org/understand/cerebral-palsy/)

Cerebral palsy (CP) is a broad diagnostic term used to describe a problem with movement and posture that makes certain activities difficult. Although someone who have cerebral palsy have problems moving his or her muscles, this is not because there is something wrong with the muscles or nerves. These difficulties are caused because of problems in the brain. Cerebral palsy can be the result of an injury to the brain during gestation or in the first year of life, or it occur when the brain does not develop properly during gestation. The injured or abnormal brain is unable to optimally control movement and posture.

Spina Bifida (http://www.mychildwithoutlimits.org/understand/spina-bifida/)

Spina bifida refers to incomplete development of the spinal cord, the meninges (the protective covering around the brain and spinal cord) and/or vertebrae with incomplete fusion of these structures such that they do not completely close over the posterior aspect of the lower spine.

Traumatic Brain Injury (http://www.ninds.nih.gov/disorders/tbi/tbi.htm)

Traumatic brain injury (TBI), a form of acquired brain injury, occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain. A person with a mild TBI may remain conscious or may experience a loss of consciousness for a few seconds or minutes. Other symptoms of mild TBI include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, bad taste in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking.

Mental Health Disabilities

IDEA Definition of Emotional Disturbance

- A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance:
- An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- Inappropriate types of behavior or feelings under normal circumstances.
- A general pervasive mood of unhappiness or depression.
- A tendency to develop physical symptoms or fears associated with personal or school problems.
- The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance. http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E8%2Cc%2C4%2C

Neurological Disabilities

Autism

- Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges. (http://www.cdc.gov/ncbddd/autism/index.html)
- Autism Speaks is a national resource with a wealth of information about autism. (http://www.autismspeaks.org/what-autism)

Fetal Alcohol Syndrome

- Fetal alcohol syndrome (FAS) is caused by maternal alcohol consumption during pregnancy. FAS is characterized by Intellectual Disability, hyperactivity, slow physical growth and (sometimes) craniofacial anomalies. In this video, an adoptive mother discusses her daughter with FAS. (https://www.youtube.com/watch?v=dTGWdcWjuZ8&list=PL24A967E728B2D56C)

Intellectual Disability

Definitions of Intellectual Disability (http://bethesdainstitute.org/page.aspx?pid=1052)

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior which covers many everyday social and practical skills.

- Video 1: What is an Intellectual Disability? This video is a brief overview of intellectual disabilities
- Video 2: What causes an Intellectual Disability? This video discusses the causation of intellectual disabilities.
- Video 3: How to Communicate with the People You Support. This video offers insight into communicating with individuals living with an intellectual disability.

Careers for People with Disabilities (https://www.youtube.com/watch?v=PhPIi9KF4Cw)

- Special Olympics Virginia athlete and Global Messenger David Egan highlights his work at Booz Allen Hamilton.

Let's Talk About Intellectual Disabilities: Loretta Claiborne at TEDxMidAtlanticLoretta (https://www.youtube.com/watch?v=0XXqr_ZSsMg)

- This video describes the hopes & dreams of children with IDD and what they hope to achieve. Claiborne's story is remarkable — from Special Olympian to inspiring speaker and advocate for others. Her work has ranged from supporting people with disabilities to working to help end bullying. In 2000, Walt Disney Productions created The Loretta Claiborne Story. "I figured if my story could change a person's mind about another person, or especially a child's mind about another child, then it was the right thing to do," Claiborne says. Loretta is a world-class runner and gifted motivational speaker who happens to also be a Special Olympics Athlete and a person who has an intellectual disability.

Sensory Disabilities

American Speech-Language-Hearing Association

- The American Speech-Language-Hearing Association (ASHA) is the national professional, scientific, and credentialing association for 182,000 members and affiliates who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students. www.asha.org)

CDC: Visual Impairment Among Children

- This factsheet is a quick overview about visual impairment among children in the United States. http://www.cdc.gov/ncbddd/developmentaldisabilities/documents/visionimpairment.pdf

American Academy of Ophthalmology

- Low vision is a loss of eyesight that makes everyday tasks difficult. A person with low vision may find it difficult or impossible to accomplish activities such as reading, writing, shopping, watching television, driving a car or recognizing faces. This website offers more information on vision loss. http://www.geteyesmart.org/eyesmart/diseases/low-vision.cfm

The Out of Sync Child

- The Out of Sync Child by Carol Kranowitz is a resource for identifying Sensory Processing Disorder, a common but frequently misdiagnosed problem in which the central nervous system misinterprets messages from the senses. Good resource to include in references or resources section. http://out-of-sync-child.com

Day 1, Module 2, Slide 41

The Individuals with Disabilities Act (IDEA)

IDEA ensures that all children with disabilities are entitled to free appropriate public education to meet their unique needs and prepare them for further education, employment, and independent living.

IDEA has four distinct sections; sections A, B, C and D.

- Part A of IDEA lays out the basic foundation for the rest of the Act. This section defines the terms used within the Act as well as providing for the creation of the Office of Special Education Programs, which is responsible for administering and carrying out the terms of IDEA (IDEA, 1997).

- Part B of IDEA is the section which lays out the educational guidelines for school children 3-21 years of age. By law, states are required to educate students with disabilities (Martin, Martin, & Terman, 1996). IDEA provides financial support for state and local school districts. However to receive funding, school districts must comply with six main principles set out by IDEA:

  1. Every child is entitled to a free and appropriate public education (FAPE).
  2. When a school professional believes that a student between the ages of 3 and 21 may have a disability that has substantial impact on the student's learning or behavior, the student is entitled to an evaluation in all areas related to the suspected disability.
  3. Creation of an Individualized Education Plan (IEP). The purpose of the IEP is to lay out a series of specific actions and steps through which educational providers, parents and the student themselves may reach the child's stated goals.
  4. That the education and services for children with disabilities must be provided in the least restrictive environment, and if possible, those children be placed in a "typical" education setting with non-disabled students.
  5. Input of the child and their parents must be taken into account in the education process.
  6. When a parent feels that an IEP is inappropriate for their child, or that their child is not receiving needed services, they have the right under IDEA to challenge their child's treatment (due process). (DREDF, 2008; Kastiyannis, Yell, Bradley, 2001; Turnbull, Huerta, & Stowe, 2004).

- Part C of IDEA recognizes the need for identifying and reaching very young children with disabilities. This portion of IDEA provides guidelines concerning the funding and services to be provides to children from birth through 2 years of age. Families are entitled to several services through Part C of IDEA (IDEA, 1997).

  1. Every family is entitled to appropriate, timely, and multidisciplinary identification and intervention services for their very young child. These services must be made available to all families with infants and toddlers.
  2. Families are required to receive an Individualized family Service Plan (IFSP). This plan lays out the priorities, resources and concerns of the family. In addition it describes the goals of the child, the services to be provided to the child, and steps for eventual transitioning of the child into formal education.
  3. Families have a right to participate in the creation of the IFSP, and must give consent prior to the initiation of intervention services.
  4. Lastly, parents are entitled to timely resolution of all conflicts or complaints regarding the evaluation or services provided to their child.

- Part D describes national activities to be undertaken to improve the education of children with disabilities. These activities include grants to improve the education and transitional services provided to students with disabilities. In addition this section provides resources to support programs, projects and activities which contribute positive results for children with disabilities (IDEA, 1997).

References

Disability Rights Education and Defense Fund. (2008). A guide for California parents: Special education due process meeting and the resolution meeting. Retrieved from http://www.dredf.org/special_education/dueprocess.pdf

Individuals with Disability Education Act Amendments of 1997 [IDEA]. (1997). Retrieved from http://thomas.loc.gov/home/thomas.php

Katsiyannis, A., Yell, M., & Bradley, R. (2001). Reflections on the 25th anniversary of the individuals with disabilities education act. *Remedial and Special Education, 22*, 324-334.

Martin, E., Martin, R., & Terman, D. (1996). The legislative and litigation history of special education. *The Future of Children, 6*, 25-39.

Turnbull, H., Huerta, N., & Stowe, M. (2004). *The Individuals with Disabilities Education Act as Amended in 2004*. Upper Saddle River, New Jersey: Pearson Education, Inc.

Source: Individuals with Disabilities Act (IDEA). American Psychological Association. http://www.apa.org/about/gr/issues/disability/idea.aspx. Retrieved on July 2, 2015.

Day 1, Module 3, Slide 60

What is child traumatic stress?

The following fact sheet discusses child traumatic stress, how it develops, and its symptoms.

This product is fee to download from the NCTSN website at
http://www.nctsnet.org/sites/default/files/assets/pdfs/what_is_child_traumatic_stress_0.pdf.

Source: National Child Traumatic Stress Network. (2013). *What is child traumatic stress?* Los Angeles, CA and Durham, NC: UCLA-Duke University National Center for Child Traumatic Stress.

NCTSN The National Child Traumatic Stress Network

What Is Child Traumatic Stress?

What is child traumatic stress, how does it develop, and what are the symptoms? To answer these questions, we first have to understand what trauma is.

From a psychological perspective, trauma occurs when a child experiences an intense event that threatens or causes harm to his or her emotional and physical well-being.

Trauma can be the result of exposure to a natural disaster such as a hurricane or flood or to events such as war and terrorism. Witnessing or being the victim of violence, serious injury, or physical or sexual abuse can be traumatic. Accidents or medical procedures can result in trauma, too. Sadly, about one of every four children will experience a traumatic event before the age of 16.

When children have a traumatic experience, they react in both physiological and psychological ways. Their heart rate may increase, and they may begin to sweat, to feel agitated and hyperalert, to feel "butterflies" in their stomach, and to become emotionally upset. These reactions are distressing, but in fact they're normal — they're our bodies' way of protecting us and preparing us to confront danger. However, some children who have experienced a traumatic event will have longer lasting reactions that can interfere with their physical and emotional health.

> Although many of us may experience reactions to stress from time to time, when a child is experiencing child traumatic stress, these reactions interfere with his or her daily life and ability to function and interact with others.

Children who suffer from child traumatic stress are those children who have been exposed to one or more traumas over the course of their lives and develop reactions that persist and affect their daily lives after the traumatic events have ended. Traumatic reactions can include a variety of responses, including intense and ongoing emotional upset, depressive symptoms, anxiety, behavioral changes, difficulties with attention, academic difficulties, nightmares, physical symptoms such as difficulty sleeping and eating, and aches and pains, among others. Children who suffer from traumatic stress often have these types of symptoms when reminded in some way of the traumatic event. Although many of us may experience these reactions from time to time, when a child is experiencing child traumatic stress, they interfere with the child's daily life and ability to function and interact with others.

Some of these children may develop ongoing symptoms that are diagnosed as post-traumatic stress disorder (PTSD). When we talk about child traumatic stress, we're talking about the stress of any child who's had a traumatic experience and is having difficulties moving forward with his or her life. When we talk about PTSD, we're talking about a disorder defined by the American Psychiatric Association as having specific symptoms: the child continues to re-experience the event through nightmares, flashbacks, or other symptoms for more than a month after the original experience; the child has what we call avoidance or numbing symptoms—he or she won't think about the event, has memory lapses, or maybe feels numb in connection with the events—and the child has feelings of arousal, such as increased irritability, difficulty sleeping, or others. Every child diagnosed with PTSD is experiencing child traumatic stress, but not every child experiencing child traumatic stress has all the symptoms for a PTSD diagnosis.

And not every child who experiences a traumatic event will develop symptoms of child traumatic stress. Whether or not your child does depends on a range of factors. These include his or her history of previous trauma exposure, because children who have experienced prior traumas are more likely to develop symptoms after a recent event. They also include an individual child's mental and emotional strengths and weaknesses and what kind of support he or she has at home and elsewhere. In some instances, when two children encounter the same situation, one will develop ongoing difficulties and the other will not. Children are unique individuals, and it's unwise to make sweeping assumptions about whether they will or will not experience ongoing troubles following a traumatic event.

For children who do experience traumatic stress, there are a wide variety of potential consequences. In addition to causing the symptoms listed earlier, the experience can have a direct impact on the development of children's brains and bodies. Traumatic stress can interfere with children's ability to concentrate, learn, and perform in school. It can change how children view the world and their futures, and can lead to future employment problems. It can also take a tremendous toll on the entire family.

Not every child who experiences a traumatic event will develop symptoms of child traumatic stress. Whether or not your child does depends on a range of factors.

The way that traumatic stress appears will vary from child to child and will depend on the child's age and developmental level. The good news is that over the past decade the mental health community has developed treatments that can help children suffering from traumatic stress. It's important to seek help from someone who has experience working with children and knows how to access resources in your community.

Although not every child will experience traumatic stress, it's unlikely that any of us are immune from exposure to trauma. To learn more about child traumatic stress, please visit the National Child Traumatic Stress Network website at www.NCTSNet.org.

This article first appeared in the fall 2003 issue of Claiming Children*, the newsletter of the Federation of Families for Children's Mental Health, www.ffcmh.org, which was co-produced by the Federation and the NCTSN.*

Day 1, Module 3, Slide 62

The 12 Core Concepts for Understanding Child Traumatic Stress

The 12 Core Concepts, developed by the NCTSN Core Curriculum Task Force, serve as the conceptual foundation of the Core Curriculum on Childhood Trauma and provide a rationale for trauma-informed assessment and intervention.

The Concepts cover a broad range of points that practitioners and agencies should consider as they strive to assess, understand, and assist trauma-exposed children, families, and communities in trauma-informed ways.

A printable version is available on the NCTSN website at http://www.nctsnet.org/resources/audiences/parents-caregivers/what-is-cts/12-core-concepts.

Source: NCTSN Core Curriculum on Childhood Trauma Task Force (2012). *The 12 core concepts: Concepts for understanding traumatic stress responses in children and families. Core Curriculum on Childhood Trauma.* Los Angeles, CA and Durham, NC: UCLA-Duke University National Center for Child Traumatic Stress.

Core Curriculum on
Childhood Trauma

The 12 Core Concepts

Concepts for Understanding Traumatic Stress Responses in Children and Families

NCTSN The National Child Traumatic Stress Network

The National Child Traumatic Stress Network

Established by Congress in 2000, the National Child Traumatic Stress Network (NCTSN) brings a singular and comprehensive focus to childhood trauma. NCTSN's collaboration of frontline providers, researchers, and families is committed to raising the standard of care while increasing access to services. Combining knowledge of child development, expertise in the full range of child traumatic experiences, and dedication to evidence-based practices, the NCTSN changes the course of children's lives by changing the course of their care.

Financial Support

This project was funded in part by the Substance Abuse and Mental Health Services Administration (SAMHSA), US Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

Citation

NCTSN Core Curriculum on Childhood Trauma Task Force (2012). *The 12 core concepts: Concepts for understanding traumatic stress responses in children and families. Core Curriculum on Childhood Trauma*. Los Angeles, CA, and Durham, NC: UCLA-Duke University National Center for Child Traumatic Stress.

Correspondence Relating to the Core Curriculum on Childhood Trauma

Anyone wishing to use any of these materials for commercial use must request and receive prior written permission from the NCTSN. Permission for such use is granted on a case-by-case basis at the sole discretion of the NCTSN. Requests for permission to adapt or license these materials, as well as general requests relating to the Core Curriculum on Childhood Trauma should be directed to the NCTSN Learning Center Help Desk at help@nctsn.org with "CCCT" in the Subject Line. General inquiries relating to products produced by the National Child Traumatic Stress Network can be directed to the NCTSN National Resource Center at info@nctsn.org. Other NCTSN products can be viewed on its website at NCTSN.org, as well as the Learning Center for Child and Adolescent Trauma at http://learn.nctsn.org/.

Acknowledgements

The Core Curriculum on Childhood Trauma is currently being developed by the NCTSN Core Curriculum on Childhood Trauma Task Force, which is made up of members and affiliates of the National Child Traumatic Stress Network (NCTSN). The foundational ideas for the Core Concepts portion of the Core Curriculum on Childhood Trauma, including the 12 Core Concepts, were developed and endorsed by the Task Force during an expert panel meeting held in August 2007. The Task Force continues to meet at NCTSN all-network conferences, via online presentations and discussions, and held a second expert panel meeting in August 2011.

NCTSN members who have served on the NCTSN Core Curriculum on Childhood Trauma Task Force since its inception in 2007 include (in alphabetical order): Robert Abramovitz, Lisa Amaya-Jackson, Harolyn Belcher, Frank Bennett, Steven Berkowitz, Lucy Berliner, Margaret Blaustein, John Briere, Judith Cohen, Kathryn Collins, Lisa Conradi, Renee Dominguez, Abigail Gewirtz, Chandra Ghosh Ippen, Jessica Gledhill, Alessia Gottlieb, (the late) Kevin Gully, Lisa Jaycox, (the late) Sandra Kaplan, Victor Labruna, Audra Langley, Alicia Lieberman, Richard Kagan, Christopher Layne (Chair), Steven Marans, Ann Masten, Lou Ann Mock, Elana Newman, David Pelcovitz, Frank Putnam, Robert Pynoos, Gilbert Reyes, Leslie Ross, Arlene Schneir, Jo Sornborger, Joseph Spinazzola, Alan Steinberg, Virginia Strand (Co-Chair), Liza Suárez, William Saltzman, Glenn Saxe, Margaret Stuber, Elizabeth Thompson, Jim Van Den Brandt, Kelly Wilson, Jennifer Wilgocki, and Marleen Wong.

Additional guidance (including attendance at Task Force meetings) has been provided by Adam Brown, Dee Foster, Mandy Habib, Donna Humbert, Laurel Kiser, Susan Ko, Peter Kung, Cheryl Lanktree, Jan Markiewicz, Cybele Merrick, Mary Mount, Frederick Strieder, Heather Langan, Bradley Stolbach, Nicole Tefera, and Patricia Van Horn.

Jennifer Galloway served as project manager for the Core Curriculum during its early years.

Gretchen Henkel, Deborah Lott, and DeAnna Griffin have provided assistance in editing, revising, and formatting the 12 Core Concepts, as well as the CCCT clinical case vignettes, and in editing and formatting the CCCT learning facilitator guides.

We gratefully acknowledge the support of SAMHSA in this endeavor, especially from project officers Malcolm Gordon and Kenneth Curl.

12 Core Concepts for Understanding Traumatic Stress Responses in Childhood

1. Traumatic experiences are inherently complex.

Every traumatic event—even events that are relatively circumscribed—is made up of different traumatic moments. These moments may include varying degrees of objective life threat, physical violation, and witnessing of injury or death. Trauma-exposed children experience subjective reactions to these different moments that include changes in feelings, thoughts, and physiological responses; and concerns for the safety of others. Children may consider a range of possible protective actions during different moments, not all of which they can or do act on. Children's thoughts and actions (or inaction) during various moments may lead to feelings of conflict at the time, and to feelings of confusion, guilt, regret, and/or anger afterward. The nature of children's moment-to-moment reactions is strongly influenced by their prior experience and developmental level. Events (both beneficial and adverse) that occur in the aftermath of the traumatic event introduce additional layers of complexity. The degree of complexity often increases in cases of multiple or recurrent trauma exposure, and in situations where a primary caregiver is a perpetrator of the trauma.

2. Trauma occurs within a broad context that includes children's personal characteristics, life experiences, and current circumstances.

Childhood trauma occurs within the broad ecology of a child's life that is composed of both child-intrinsic and child-extrinsic factors. Child-*intrinsic* factors include temperament, prior exposure to trauma, and prior history of psychopathology. Child-*extrinsic* factors include the surrounding physical, familial, community, and cultural environments. Both child-intrinsic and child-extrinsic factors influence children's experience and appraisal of traumatic events; expectations regarding danger, protection, and safety; and course of posttrauma adjustment. For example, both child-intrinsic factors such as prior history of loss, and child-extrinsic factors such as poverty may act as vulnerability factors by exacerbating the adverse effects of trauma on children's adjustment.

3. Traumatic events often generate secondary adversities, life changes, and distressing reminders in children's daily lives.

Traumatic events often generate secondary adversities such as family separations, financial hardship, relocations to a new residence and school, social stigma, ongoing treatment for injuries and/or physical rehabilitation, and legal proceedings. The cascade of changes produced by trauma and loss can tax the coping resources of the child, family, and broader community. These adversities and life changes can be sources of distress in their own right and can create challenges to adjustment and recovery. Children's exposure to trauma reminders and loss reminders can serve as additional sources of distress. Secondary adversities, trauma reminders, and loss reminders may produce significant fluctuations in trauma survivors' posttrauma emotional and behavioral functioning.

4. Children can exhibit a wide range of reactions to trauma and loss.

Trauma-exposed children can exhibit a wide range of posttrauma reactions that vary in their nature, onset, intensity, frequency, and duration. The pattern and course of children's posttrauma reactions are influenced by the type of traumatic experience and its consequences, child-intrinsic factors including prior trauma or loss, and the posttrauma physical and social environments. Posttraumatic stress and grief reactions can develop over time into psychiatric disorders, including posttraumatic stress disorder (PTSD), separation anxiety, and depression. Posttraumatic stress and grief reactions can also disrupt major domains of child development, including attachment relationships, peer relationships, and emotional regulation, and can reduce children's level of functioning at home, at school, and in the community. Children's posttrauma distress reactions can also exacerbate preexisting mental health problems including depression and anxiety. Awareness of the broad range of children's potential reactions to trauma and loss is essential to competent assessment, accurate diagnosis, and effective intervention.

5. Danger and safety are core concerns in the lives of traumatized children.

Traumatic experiences can undermine children's sense of protection and safety, and can magnify their concerns about dangers to themselves and others. Ensuring children's physical safety is critically important to restoring the sense of a protective shield. However, even placing children in physically safe circumstances may not be sufficient to alleviate their fears or restore their disrupted sense of safety and security. Exposure to trauma can make it more difficult for children to distinguish between safe and unsafe situations, and may lead to significant changes in their own protective and risk-taking behavior. Children who continue to live in dangerous family and/or community circumstances may have greater difficulty recovering from a traumatic experience.

6. Traumatic experiences affect the family and broader caregiving systems.

Children are embedded within broader caregiving systems including their families, schools, and communities. Traumatic experiences, losses, and ongoing danger can significantly impact these caregiving systems, leading to serious disruptions in caregiver-child interactions and attachment relationships. Caregivers' own distress and concerns may impair their ability to support traumatized children. In turn, children's reduced sense of protection and security may interfere with their ability to respond positively to their parents' and other caregivers' efforts to provide support. Traumatic events—and their impact on children, parents, and other caregivers—also affect the overall functioning of schools and other community institutions. The ability of caregiving systems to provide the types of support that children and their families need is an important contributor to children's and families' posttrauma adjustment. Assessing and enhancing the level of functioning of caregivers and caregiving systems are essential to effective intervention with traumatized youths, families, and communities.

7. Protective and promotive factors can reduce the adverse impact of trauma.

Protective factors buffer the adverse effects of trauma and its stressful aftermath, whereas *promotive* factors generally enhance children's positive adjustment regardless of whether risk factors are present. Promotive and protective factors may include *child-intrinsic* factors such as high self-esteem, self-efficacy, and possessing a repertoire of adaptive coping skills. Promotive and protective factors may also include *child-extrinsic* factors such as positive attachment with a primary caregiver, possessing a strong social support network, the presence of reliable adult mentors, and a supportive school and community environment. The presence and strength of promotive and protective factors—both before and after traumatic events—can enhance children's ability to resist, or to quickly recover (by resiliently "bouncing back") from the harmful effects of trauma, loss, and other adversities.

8. Trauma and posttrauma adversities can strongly influence development.

Trauma and posttrauma adversities can profoundly influence children's acquisition of developmental competencies and their capacity to reach important developmental milestones in such domains as cognitive functioning, emotional regulation, and interpersonal relationships. Trauma exposure and its aftermath can lead to developmental disruptions in the form of regressive behavior, reluctance, or inability to participate in developmentally appropriate activities, and developmental accelerations such as leaving home at an early age and engagement in precocious sexual behavior. In turn, age, gender, and developmental period are linked to risk for exposure to specific types of trauma (e.g., sexual abuse, motor vehicle accidents, peer suicide).

9. Developmental neurobiology underlies children's reactions to traumatic experiences.

Children's capacities to appraise and respond to danger are linked to an evolving neurobiology that consists of brain structures, neurophysiological pathways, and neuroendocrine systems. This "danger apparatus" underlies appraisals of dangerous situations, emotional and physical reactions, and protective actions. Traumatic experiences evoke strong biological responses that can persist and that can alter the normal course of neurobiological maturation. The neurobiological impact of traumatic experiences depends in part on the developmental stage in which they occur. Exposure to multiple traumatic experiences carries a greater risk for significant neurobiological disturbances including impairments in memory, emotional regulation, and behavioral regulation. Conversely, ongoing neurobiological maturation and neural plasticity also create continuing opportunities for recovery and adaptive developmental progression.

10. Culture is closely interwoven with traumatic experiences, response, and recovery.

Culture can profoundly affect the meaning that a child or family attributes to specific types of traumatic events such as sexual abuse, physical abuse, and suicide. Culture may also powerfully influence the ways in which children and their families respond to traumatic events including the ways in which they experience and express distress, disclose personal information to others, exchange support, and seek help. A cultural group's experiences with historical or multigenerational trauma can also affect their responses to trauma and loss, their world view, and their expectations regarding the self, others, and social institutions. Culture also strongly influences the rituals and other ways through which children and families grieve over and mourn their losses.

11. Challenges to the social contract, including legal and ethical issues, affect trauma response and recovery.

Traumatic experiences often constitute a major violation of the expectations of the child, family, community, and society regarding the primary social roles and responsibilities of influential figures in the child's life. These life figures may include family members, teachers, peers, adult mentors, and agents of social institutions such as judges, police officers, and child welfare workers. Children and their caregivers frequently contend with issues involving justice, obtaining legal redress, and seeking protection against further harm. They are often acutely aware of whether justice is properly served and the social contract is upheld. The ways in which social institutions respond to breaches of the social contract may vary widely and often take months or years to carry out. The perceived success or failure of these institutional responses may exert a profound influence on the course of children's posttrauma adjustment, and on their evolving beliefs, attitudes, and values regarding family, work, and civic life.

12. Working with trauma-exposed children can evoke distress in providers that makes it more difficult for them to provide good care.

Mental healthcare providers must deal with many personal and professional challenges as they confront details of children's traumatic experiences and life adversities, witness children's and caregivers' distress, and attempt to strengthen children's and families' belief in the social contract. Engaging in clinical work may also evoke strong memories of personal trauma- and loss-related experiences. Proper self-care is an important part of providing quality care and of sustaining personal and professional resources and capacities over time.

DSM-5 Criteria for Posttraumatic Stress Disorder (PTSD)

- PTSD is in response to exposure to actual or threatened death, serious injury or sexual violation. The exposure must result from one or more of the following scenarios, in which the individual:
    - directly experiences the traumatic event;
    - witnesses the traumatic event in person;
    - learns that the traumatic event occurred to a close family member or close friend (with the actual
- or threatened death being either violent or accidental); or
- experiences first-hand repeated or extreme exposure to aversive details of the traumatic event (not through media, pictures, television or movies unless work-related). The disturbance, regardless of its trigger, causes clinically significant distress or impairment in the individual's social interactions, capacity to work or other important areas of functioning. It is not the physiological result of another medical condition, medication, drugs or alcohol.
- 4 distinct diagnostic clusters:
- Re-experiencing covers spontaneous memories of the traumatic event, recurrent dreams related to it, flashbacks or other intense or prolonged psychological distress.
- Avoidance refers to distressing memories, thoughts, feelings or external reminders of the event.
- Negative cognitions and mood represents myriad feelings, from a persistent and distorted sense of blame of self or others, to estrangement from others or markedly diminished interest in activities, to an inability to remember key aspects of the event.
- Arousal is marked by aggressive, reckless or self-destructive behavior, sleep disturbances, hyper- vigilance or related problems. The current manual emphasizes the "flight" aspect associated with PTSD; the criteria of DSM-5 also account for the "fight" reaction often seen.

Source: American Psychiatric Association. (2013*). Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Resources for Gentle Teaching, Positive Behavior Support & Positive Identity Development

Gentle Teaching

Gentle teaching was developed in the eighties by John McGee. In the early years gentle teaching was especially known as an approach for helping people with an intellectual disability and severe behavior problems.

- The first and most important goal in gentle teaching is to develop companionship, the unconditional relationship which makes it possible to support the person in moments of stress. A side-effect may be the prevention of harmful behaviors. But this is not a goal in gentle teaching.
- After companionship has been established, the goal is to support the person in his/her personal development and in realizing his/her dreams. As a result his/her quality of life will improve and the causes of stress will further decrease.
- For more information and resources on Gentle Teaching, go to the Gentle Teaching website at http://www.gentleteaching.nl/gentle/index.php/en/.

Positive Behavior Support

A set of systems, tools and processes for organizing the social, educational, biomedical, physical, and logistical supports needed to help individuals across the lifespan achieve a higher quality of life while reducing problem behaviors that may prevent positive outcomes for these individuals. The core defining features of positive behavior support include:

- The application of evidence-based applied behavioral and biomedical science;
- Integration of environmental and emotional, physiological, and biomedical supports;
- Ecologically valid, practical interventions that reflect the values, skills, and resources of the individual and his/her team (also referred to as *contextual fit*);
- Commitment to socially important and durable lifestyle outcomes; and
- Implementation of support within family and organizational systems to ensure sustainable change over time.
- For more information and resources on PBS, go to the Kansas Institute for Positive Behavior Support website at http://www.kipbs.org/new_kipbs/basicInfo/basic.html#what.

Positive Identity Development

Positive Identity Development is a new approach to caring for individuals with intellectual disabilities, developed by Karyn Harvey, PhD. It rejects reducing adults with intellectual disabilities to a mere compilation of their behaviors and instead nurtures each individual's sense of identity.

- See Karyn Harvey's book, *Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities* (2009, NADD Press) for a variety of innovative tools. There are additional forms and workbooks that can be downloaded free of charge to be used with clients—available online at http://pid.thenadd.org.

Day 2, Module 4, Slide 23

NCTSN Sites

Trauma-informed services and treatments are available at all National Child Traumatic Stress Network centers with the common goal of reducing the impact of exposure to traumatic events on children and adolescents. A list of NCTSN Centers, both currently funded and affiliate sites, is available on the NCTSN website at http://www.nctsn.org/about-us/network-members.

Resources for Families

University Centers for Excellence in Developmental Disabilities (UCEDDS) & AUCD

- Since 1963, University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) have been working to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision. Currently, sixty-seven UCEDDs in every state and territory are located in a university setting. http://www.acl.gov/NewsRoom/Publications/docs/AIDDfactsheet.pdf
- State Program Directory: http://www.aucd.org/directory/directory.cfm?program=UCEDD

Center for Parent Information & Resources

- Families with a child who has a disability often need information about the disability of their child, about early intervention, school services, therapy, local policies, transportation, and much more. Every State has at least one Parent Training and Information Center (PTI) to offer families just this kind of information. Many States also have a Community Parent Resource Center (CPRC), which offers the same type of support and training to parents of children with disabilities. http://www.parentcenterhub.org/find-your-center/
- For a quick read on what PTIs and CPRCs do, and how they can help parents and families of children with disabilities: http://www.parentcenterhub.org/wp-content/uploads/repo_items/bp3.pdf

Early Childhood Technical Assistance Center

- A resource to help families understand their rights under the Individuals with Disabilities Education Act (IDEA), connect with other families, and find high-quality resources related to caring for infants, toddlers and young children with disabilities. http://ectacenter.org/families.asp

The Arc

- For more than 60 years, The Arc has been on the front lines in making change happen for people diagnosed with Autism, Down syndrome, Fetal Alcohol Spectrum Disorder, and a range of diagnoses across the spectrum of intellectual and developmental disabilities. The Arc is the nation's leading advocate for all people with intellectual and developmental disabilities and their families and the premier provider of the supports and services people want and need. http://www.thearc.org/

Understood

- A resource to help parents whose children, ages 3-20, are struggling with learning and attention issues. Understood.org seeks to empower parents to understand their children’s issues and relate to their experiences. https://www.understood.org/en

Federation of Families for Children’s Mental Health

- The National Federation of Families for Children’s Mental Health is a national family-run organization linking more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and their families. It was conceived in Arlington, Virginia in February, 1989 by a group of 18 people determined to make a difference in the way the system works.
  https://www.ffcmh.org/chapters

Family Voices

- Family Voices is a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs. Working with family leaders and professional partners at the local, state, regional and national levels since 1992, Family Voices has brought a respected family perspective to improving health care programs and policies and ensuring that health care systems include, listen to, and honor the voices of families.
  http://www.familyvoices.org/

The NADD: An Association for People with Intellectual Disabilities & Mental Health Needs

- NADD is a not-for-profit membership association established for professionals, care providers and families to promote understanding of and services for individuals who have developmental disabilities and mental health needs. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.
  http://theNadd.org

National Disability Rights Network (Protection & Advocacy Centers)

- The National Disability Rights Network (NDRN) works to improve the lives of people with disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems. NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the Network is the largest provider of legally based advocacy services to people with disabilities in the United States.
  http://www.ndrn.org/about/paacap-network.html

Sensory Street: Strategies for Whole Child Success

- Via workshops, community events, school in-services, at-home consultations and more, sensory street supports differently-abled children and the grownups in their lives by offering information on a wide variety of strategies that nourish mind, body and spirit. The website has a number of free, downloadable resources.
  http://www.sensorystreet.com/resources.html

Day 2, Module 5, Slide 33

Developmental Surveillance & Screening

Recommendations developed by the American Academy of Pediatrics, Committee on Children with Disabilities:

To screen for developmental delays or disabilities and intervene with the identified children and their families, the primary pediatrician providing the medical home should:

1. Maintain and update her or his knowledge about developmental issues, risk factors, screening techniques, and community resources, such as early intervention, school, Title V, and other community-based programs, for consultation, referral, and intervention.
2. Acquire skills in the administration and interpretation of reliable and valid developmental screening techniques appropriate for the population.
3. Develop a strategy to provide periodic screening in the context of office-based primary care, including the following:
    a. Recognizing abnormal appearance and function during health care maintenance examinations;
    b. Recognizing medical, genetic, and environmental risk factors while taking routine medical, family, and social histories;
    c. Listening carefully to parental concerns and observations about the child's development during all encounters;
    d. Recognizing troubled parent-child interaction by reviewing history or by observation;
    e. Performing periodic screenings of all infants and young children during preventive care visits; and
    f. Recognizing the importance that test procedures and processes be culturally sensitive and appropriate to the population.
4. Present the results of the screening to the family using a culturally sensitive, family-centered approach.
5. With parental agreement, refer children with developmental delays in a timely fashion to the appropriate early intervention and early childhood education programs and other community-based programs serving infants and young children.
6. Determine the cause of delays or refer to appropriate consultant for determination. Screen hearing and vision to rule out sensory impairments.
7. Maintain links with community-based resources, such as early intervention, school, and other community-based programs, and coordinate care with them.
8. Increase parents' awareness of developmental disabilities and resources for intervention by such methods as display and distribution of educational materials in the office.
9. Be available to families to interpret consultants' findings.

Source: Recommendations listed in the AAP 2001 Pediatrics Journal Article: Developmental Surveillance & Screening of Infants and Young Children, re-written in 2006 & reaffirmed in 2014, *Pediatrics 134:6*

Day 2, Module 5, Slide 48

Recovery Plans & Person-Centered Planning Tools

Essential Lifestyle Planning

- ELP is a guided process designed to help an individual discover and attain what matters most to them and identify what supports might be needed. Discussions related to health and safety are an integral part of this process. The discoveries made during this guided process are described so that they are understood by all participants including the focus person and his or her family.
- Visit The Learning Center for Person-Centered Practices for sample plans and more information: http://www.learningcommunity.us/sample_plans.htm.

Personal Futures Planning

- Personal Futures Planning, sometimes also known as Person-Centered Planning, is a process to assist teams to plan for the next stage of an individual's life. Typically the team includes a person's family and teacher or rehabilitation worker, as well as friends, neighbors, and people of significance in the individual's life. They gather together with the target-person to focus on the future, with an emphasis on what the individual likes and what they can do, rather than on a pre-defined outcome.

Planning Alternative Tomorrows with Hope (PATH)

- The PATH Program aims to help individuals with disabilities, and their families, to achieve life goals through the use of graphic and visual planning tools that work towards turning their aspirations and dreams into real and possible futures.

Making Action Plans (MAPS)

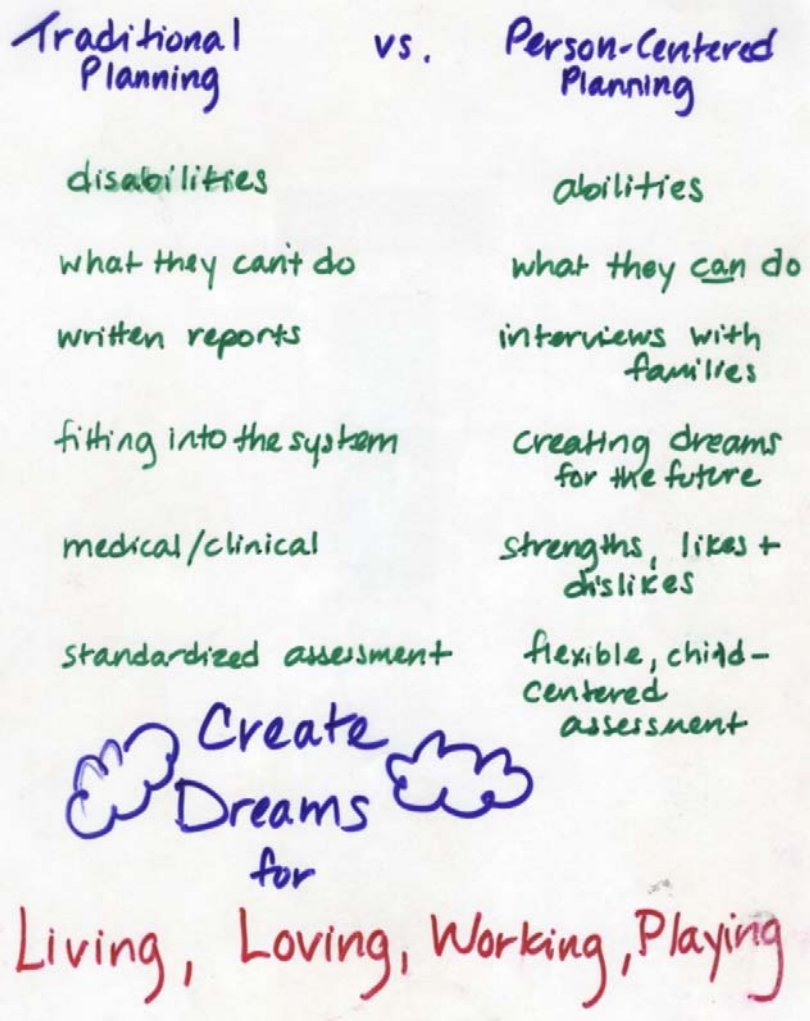
- Through a series of questions, individuals and organizations help individuals with disabilities construct a personal history or life story based on personal milestones. After getting to know the individual better and exploring his or her dreams for the future, the team begins to build a plan to move in the direction of the individual’s dreams.

Individual Family Service Plan (IFSP)

- An IFSP is a plan for special services for young children with developmental delays. An IFSP only applies to children from birth to three years of age.
- See a sample IFSP plan: http://www.sagepub.com/gargiulo3estudy/pdf/Gargiulo_IFSP.pdf

Individualized Education Plan (IEP)

- Once a child turns 3 years old, an **Individualized** Education Program (IEP) is put into place. **An** IEP is the legal document that defines a child's learning needs, the services the school will provide and how a child's progress will be measured.
- **For more information, visit Understood: For Learning & Attention Issues at** https://www.understood.org/en/school-learning/special-services/ieps/understanding-individualized-education-programs



Traditional Planning	vs.	Person-Centered Planning
disabilities		abilities
what they can't do		what they can do
written reports		interviews with families
fitting into the system		creating dreams for the future
medical/clinical		strengths, likes + dislikes
standardized assessment		flexible, child-centered assessment

Create Dreams for

Living, Loving, Working, Playing

Source: Transition Planning Asia: Preparing Youth who are Blind or Visually Impaired with Multiple Disabilities for Adult Life. http://www.transitionplanningasia.org/what-personal-futures-planning. Retrieved on July 2, 2015.

Day 2, Module 5, Slide 49

Empirically Supported Trauma-Informed Treatments & Promising Practices

Name of Intervention	Targeted Populations	Modality	Culture-Specific Fact Sheet
Adapted Dialectical Behavior Therapy for Special Populations (DBT-SP) (2012) (PDF)	8-21; both males and females; for youth experiencing a wide range of traumas	individual	Yes
Alternatives for Families - A Cognitive Behavioral Therapy (AF-CBT) (2012) (PDF)	School-age children; for youth experiencing a wide range of traumas	individual, family	Yes
Assessment-Based Treatment for Traumatized Children: Trauma Assessment Pathway (TAP) (2012) (PDF)	0-18; both males and females; for children who have experienced a wide range of traumas	individual, family, systems	Yes
Attachment and Biobehavioral Catch-up (ABC) (2012) (PDF)	Birth – 24 months; both males and females; for low-income families who have experienced neglect, abuse, domestic violence, placement instability	individual, family	No
Attachment, Self-Regulation, and Competence (ARC): A Comprehensive Framework for Intervention with Complexly Traumatized Youth (2012) (PDF)	2-21; both males and females; for children, caregivers, and systems that have experienced a wide range of traumas	individual, family, systems	Yes
Child Adult Relationship Enhancement (CARE) (2008) (PDF)	Children of all ages and their caregivers; both males and females	family, systems	Yes
Child and Family Traumatic Stress Intervention (CFTSI) (2012) (PDF)	7-18; both males and females; for parents and children who may have complex trauma histories	individual, family, systems	No
Child Development-Community Policing Program (2007) (PDF)	0-18+; both males and females; for children and families in the aftermath of crime and violence.	individual, family, systems	No
Child-Parent Psychotherapy (CPP) (2012) (PDF)	0-6; both males and females; for youth who have experienced a wide range of traumas and parents with chronic trauma	individual, family, systems	Yes
Cognitive Behavioral Intervention for Trauma in Schools (CBITS) (2012) (PDF)	10-15; both males and females; for children who have experienced a wide range of traumas	individual, family, systems	Yes

Name of Intervention	Targeted Populations	Modality	Culture-Specific Fact Sheet
Combined Parent Child Cognitive-Behavioral Approach for Children and Families At-Risk for Child Physical Abuse (CPC-CBT) (2009) (PDF)	4-17; both male and female; for families with a history of physical abuse and inappropriate physical discipline/coercive parenting strategies	individual, group, family	Yes
Combined TF-CBT and SSRI Treatment (2007) (PDF)	10-18; females	individual, family	No
COPE - Community Outreach Program - Esperanza (2007) (PDF)	4-18; both males and females; for children who are presenting with behavior or social-emotional problems	individual, family	No
Culturally Modified Trauma-Focused Treatment (CM-TFT)(2008) (PDF)	4-18; both males and females; Latino/Hispanic; for youth who have experienced a wide range of traumas	individual, family	Yes
Family Advocate Program (2005) (PDF)	18-70; both males and females; for youth who present with anxiety, depression, PTSD symptoms, and/or traumatic loss	family	No
Forensically-Sensitive Therapy (2005) (PDF)	4-17; predominantly female; for youth presenting problems ranging from anxiety and depression to risk-taking behaviors and functional impairment. Program is designed for a mental health clinic.	individual, family	No
Group Treatment for Children Affected by Domestic Violence (2007) (PDF)	5-no upper limit; both males and females; for children and their nonoffending parents who have been exposed to DV	group, family, systems	No
Honoring Children, Making Relatives (2007) (PDF)	3-7; both males and females; for American Indian and Alaska Native children	individual, family	No
Honoring Children, Mending the Circle (2007) (PDF)	3-18; both males and females; for American Indian and Alaska Native children	individual	No
Honoring Children, Respectful Ways (2007) (PDF)	3-12; both males and females; for American Indian and Alaska Native children	individual	No
Integrative Treatment of Complex Trauma (ITCT-C, ITCT-A) (2008) (PDF)	2-21; both males and females; for Hispanic-American, African-American, Caucasian, Asian-American; for youth who may have complex trauma histories	individual, family, systems	Yes
International Family Adult and Child Enhancement Services (IFACES) (2012) (PDF)	6-12; both males and females; for refugee and immigrant children who have experienced trauma as a result of war or displacement	individual	Yes

Name of Intervention	Targeted Populations	Modality	Culture-Specific Fact Sheet
Parent-Child Interaction Therapy (PCIT) (2008) (PDF)	2-12; both males and females	individual, family, systems	Yes
Psychological First Aid (PFA) (2012) (PDF)	0-120; both males and females; for individuals immediately following disasters, terrorism, and other emergencies	individual	Yes
Real Life Heroes (RLH) (2012) (PDF)	6-12, plus adolescents (13-19) with delays in social, emotional or cognitive functioning; both males and females; for children who have experienced a wide range of traumas	individual, family, systems	Yes
Safe Harbor Program (2007) (PDF)	6-21; both males and females; provided in schools for children and adolescents exposed to trauma and violence who may present with a range of problems and symptoms	individual, group, family, systems	No
Safety, Mentoring, Advocacy, Recovery, and Treatment (SMART) (2012) (PDF)	3-11; both males and females; to date the model has been effectively used with primarily African-American children; majority of families are low income	individual, family, systems	No
Sanctuary Model (2008) (PDF)	4-no upper limit; both males and females; evidence-supported template for system change based on the active creation and maintenance of a nonviolent, democratic, productive community to help people heal from trauma	systems	Yes
Sanctuary Model Plus (IRIS Project)(2005) (PDF)	Children and adolescents placed in residential treatment centers and their families	group, systems	No
Skills for Psychological Recovery (SPR)(2012) (PDF)	5-120; both males and females	individual, family	Yes
Skills Training in Affective and Interpersonal Regulation/Narrative Story-Telling (STAIR/NST) (2005) (PDF)	12-21; for females who have experienced sexual/physical abuse and a range of additional traumas, including community violence, domestic violence, and sexual assault	individuals, group	No
Southeast Asian Teen Village (2005) (PDF)	adolescents; females, Southeast Asian (mostly Hmong)	group	No
Streetwork Project (2007) (PDF)	13-23; both males and females; harm reduction program good with a wide variety of ethnic/racial groups, religious group, and the LGBTQ community	individuals, group, system	No

Name of Intervention	Targeted Populations	Modality	Culture-Specific Fact Sheet
Strengthening Family Coping Resources (SFCR) (2008) (PDF)	0-no upper limit; both males and females; for families experiencing economic hardship	family	No
Structured Psychotherapy for Adolescents Responding to Chronic Stress (SPARCS)(2012) (PDF)	12-21; both males and females; for adolescents with Complex Trauma, e.g. adolescents exposed to chronic interpersonal trauma (such as ongoing physical abuse) and/or separate types of trauma (e.g. community violence, sexual assault).	group	Yes
Trauma Adapted Family Connections (TA-FC) (2012) (PDF)	0-18; both males and females; who reside in the household; families experiencing complex development trauma, at risk of neglect	individual, family, group	No
Trauma Affect Regulation: Guidelines for Education and Therapy (TARGET) (2012) (PDF)	10-18+; both males and females; for children and caregivers experiencing traumatic stress; very frequently with single parents or with families whose children have limited contact with biological parents (e.g., foster kids, residential placements), and diversity of religious affiliations	individual, group, family, systems	Yes
Trauma and Grief Component Therapy for Adolescents (TGCT-A) (2015) (PDF)	12-20; both males and females; for trauma-exposed or traumatically bereaved older children and adolescents	individual, group, family, systems	Yes
Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) (2012) (PDF)	3-21; both males and females; for children with Posttraumatic Stress Disorder (PTSD) or other problems related to traumatic life experiences, and their parents or primary caregivers	individual, family	Yes
Trauma-Focused Coping in Schools (TFC) (AKA: Multimodality Trauma Treatment Trauma-Focused Coping-MMTT) (2012) (PDF)	6-18; both males and females; for children exposed to single incident trauma and targets posttraumatic stress disorder (PTSD) and collateral symptoms of depression, anxiety, anger, and external locus of control	individual, group	Yes
Trauma-Informed Organizational Self-Assessment (2008) (PDF)	6-19; both males and females; for children who have experienced a wide range of traumas	individual, family, systems	Yes
Trauma Systems Therapy (TST) (2008) (PDF)	6-19; both males and females; for youth who have experienced a wide range of traumas	systems	Yes

Day 2, Module 5, Slide 57

Effective Strategies Checklist

The National Technical Assistance Center for Children's Mental Health at Georgetown University Center for Child and Human Development developed the following checklist. Children and youth who have intellectual disabilities or developmental disorders are at elevated risk for co0occurring psychiatric or behavioral problems. These young people pose a serios challenge for administrators, program directors and clinicians, especially when they rpesent 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 fmialies 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 justices and child welfare.

This checklist is available at http://gucchdtacenter.georgetown.edu/publications/Effective%20Strategies%20Checklist%20FINAL.pdf.

Source: National Technical Assistance Center for Children's Mental Health. (2014). *Effective Strategies Checklist: Children and Youth with Developmental Disorders and Challenging Behavior.* Washington, DC: Georgetown University Center for Child and Human Development.

Reprinted with permission.

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.

National Technical
Assistance Center for
Children's Mental Health
GEORGETOWN UNIVERSITY CENTER FOR CHILD AND HUMAN DEVELOPMENT

☐ **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/pbPavingTheWayMonograph.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.

Additional Sources

Baker, D., & Blumberg, R. (Eds.). (2013). *Mental health and wellness supports for children and youth with intellectual disabilities.* Kingston, NY: NADD Press.

Beasley, J. B. (2005). Crisis prevention and management. In L. Rubin & A. C. Crocker (Eds.), *Medical care for children and adults with developmental disabilities* (pp. 510-517). Baltimore, MD: Paul H. Brookes Publishing.

Beasley, J. B. (2010, July). *Effective services and supports for children and youth with co-occurring developmental disabilities and mental health challenges: START: Systemic, Therapeutic, Assessment, Respite and Treatment.* Presented at the Georgetown Training Institutes, Washington, DC. Available at http://gucchdtacenter.georgetown.edu/resources/Training%20Institutes/Institutes/I13/I13_Beasley.pdf.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., Deutsch, C. (2011). Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *J Intellect Disabil Res, 55*(2), 199-209.

Charlton, M., & Dykstra, E. J., (2011). Dialectical behavior therapy for special populations: Treatment with adolescents and their caregivers. *Advances in Mental Health and Intellectual Disabilities, 5*(5), 6-14. Permanent link to this document: http://dx.doi.org/10.1108/20441281111180619.

Davis, M., Jivanjee, P., & Koroloff, N. (2010). *Paving the way: Meeting transition needs of young people with developmental disabilities and serious mental health conditions.* Portland, OR: Research and Training Center on Family Support and Children's Mental Health. Accessed online at http://www.rtc.pdx.edu/PDF/pbPavingTheWayMonograph.pdf.

Einfeld, S. L., Ellis, L. A., Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *J Intellect Dev Disabilities, 36*(2), 137-43.

Fletcher, R. (2011). *Psychotherapy for individuals with intellectual disability.* Kingston, NY: NADD Press.

Jacobstein, D. M., Stark, D. R., Laygo, R. M. (2007). Creating responsive systems for children with co-occurring developmental and emotional disorders. *Mental Health Aspects of Developmental Disabilities, 10*(3), 91-98.

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., Tager-Flusberg, H., & Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. J*ournal of Autism and Developmental Disorders, 36*(7), 849-61.

Mann, C. (2013). *CMCS Informational Bulletin: Prevention and early identification of mental health and substance use conditions.* Accessed online at http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-03-27-2013.pdf.

Mann, C. & Hyde, P.S. (2013). *Joint CMCS and SAMHSA informational bulletin: Coverage of behavioral health services for children, youth, and young adults with significant mental health conditions.* Retrieved from http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-05-07-2013.pdf.

Maryland Coalition of Families for Children's Mental Health. (2010, May). *Listening and learning from families caring for a child with co-occurring disorders: Mental health, substance abuse, developmental disabilities.* Maryland: Author. Available at http://www.mdcoalition.org.

Pires, S. (2010). *Building systems of care: A primer, 2nd edition.* Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.

Pitonyak, D. (2010). *The importance of belonging.* Retrieved from http://www.hsri.org/files/NCRI/Belonging.pdf.

Sheldon, G. H., Tavenner, M., & Hyde, P. S. (2013). *Letter to state Medicaid directors from the Department of Health and Human Services.* Retrieved from http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-07-11.pdf.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *J. Am. Acad. Child Adolesc. Psychiatry, 47*(8), 921-929.

Stroul, B. A., Blau, G. M., Friedman, R. M. (2010). *Updating the system of care concept and philosophy.* Washington, DC: National Technical Assistance Center for Children's Mental Health. Available at http://gucchdgeorgetown.net/data/issues/2010/0910_article.html.

Wotring, J. R., & Stroul, B. A. (2011). **Issue brief: The intersection of health reform and systems of care for children and youth with mental and substance use disorders and their families.** Washington, DC: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health.

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. Please contact Diane M. Jacobstein, PhD (jacobstd@georgetown.edu) for further information.

Special thanks to Jim Wotring, MSW and Sherry Peters, MSW, ACSW of the Georgetown National TA Center for Children's Mental Health and Eileen Elias, MEd of JBS International for their inspiration, critical thinking and generous assistance.