Special Population: Children with Intellectual and other Developmental Disabilities

Cindy Mowris, Educator
New York Alliance for Inclusion and Innovation

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Presentation Created by

NEW YORK
ALLIANCE FOR
INCLUSION & INNOVATION

240 Washington Avenue Ext., Suite 501, Albany, NY 12203
Phone: 518-795-3590 **Web:** NYALLIANCE.ORG

*The **New York Alliance for Inclusion and Innovation (New York Alliance)** envisions a society where individuals with disabilities are contributing citizens with equal rights and the ability to live full, productive and meaningful lives.*

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Covered Today

- Children who have Intellectual and other Developmental Disabilities (I/DD)
- Children with I/DD who are Medically Fragile
- Children with I/DD in Foster Care
- Effect of Children's System Transformation on I/DD Medically Fragile and I/DD in Foster Care

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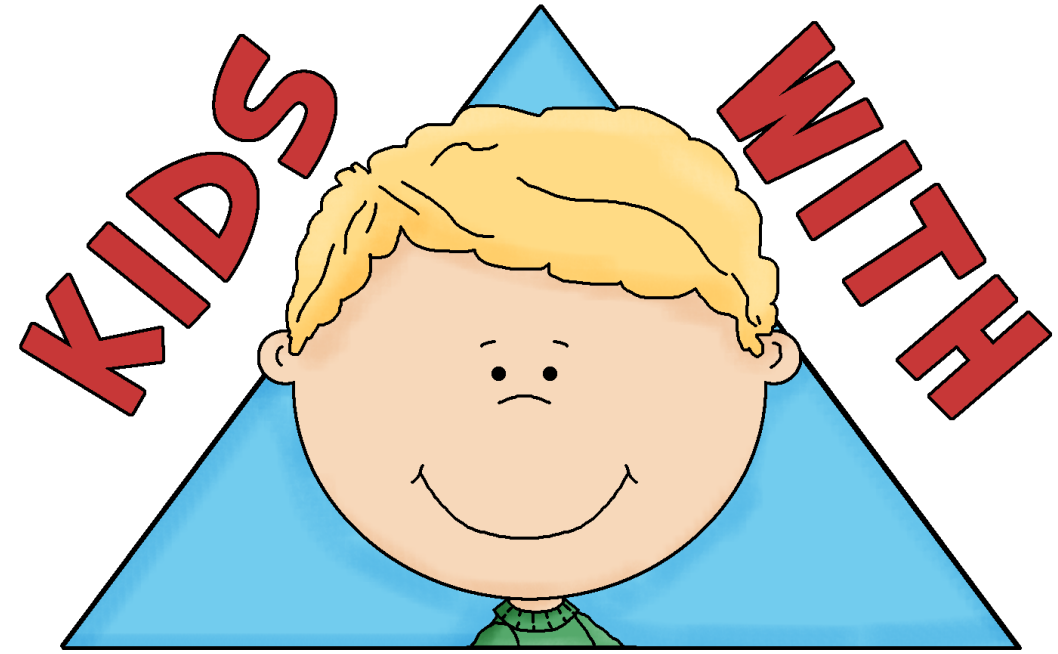

DISABILITIES

ARE JUST KIDS

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Important to Remember

People First

- Kids are Not alone (individual, family, professional)
- Supports required for all involved
- Unique amazing individual
- Hopes, dreams & desires
- Equal rights & privileges
- Dignity of risk
- Potential trauma

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What is a Developmental Disability? AKA: DD/IDD

- Occurs before age 22
- Is lifelong
- Impacts physical, intellectual and/or emotional development
- Can affect language, mobility, learning, self-help and independent living

<u>Identified by observable characteristics:</u>

- Depends on the DD/IDD

<u>General Observable Impact on Individual:</u>

- Attention problems
- Impulsivity / Distractibility
- Comprehension / memory problems
- Lack of appropriate social, emotional and leisure skills

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Examples of Developmental Disabilities

- Down syndrome - distinct physical features. Small skull, upward slant of eyes and epicanthic folds, oblique palpebral fissure, nose is small with the flat nasal bridge, mouth has a narrow short palate with small teeth and furrowed protruding tongue

- Autism Spectrum Disorders (ASD) - may appear A-typical at a glance. Lack of interest in others, poor eye contact, communication challenges, (sometimes non-verbal), hand flapping, body rocking, narrow range of interests

- Cerebral Palsy - muscle tightness or spasticity, Involuntary movement, disturbance in gait or mobility, difficulty swallowing, problems with speech

- Spina Bifida - a sac of fluid comes through an opening in the baby's back. sometimes called "hidden" spina bifid

- Fragile X Syndrome - prominent ears, macroorchidism (enlarged testicles), double-jointed fingers, flat feet, puffy eyelids, and "hollow chest

- Co-occurring

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Supporting Children as They Develop

Birth to 2 years old (Infancy)

- Developmental challenges

  https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

- Changing family expectations
  - Family dynamics with a child with differing abilities
  - Parents and families generally have limited knowledge and resources or know where to find them.
- Services available- see resource list for more information
  - New York State Department of Health, Division of Family Health, Bureau of Early Intervention www.health.ny.gov/community/infants_children/early_intervention/
  - https://www.eifamilies.com/

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Supporting Children as They Develop

2 to 4 years old (Toddler)

Developmental challenges - missing milestones

- Can't jump in place
- Has trouble scribbling
- Shows no interest in interactive games or make-believe
- Ignores other children or doesn't respond to people outside the family
- Resists dressing, sleeping, and using the toilet
- Can't retell a favorite story
- Doesn't follow 3-part commands
- Doesn't understand "same" and "different"
- Doesn't use "me" and "you" correctly
- Speaks unclearly
- Loses skills they once had

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Supporting Children as They Develop

2 to 4 years old (Toddler)

- Changing family expectations & concerns
  - Effects on sibling- taking time and attention from them
  - Family stress
  - Those associated with normal growth & development, self care, safety concerns, eating/dietary needs, personal care
- Services available - see resource list
  - Early intervention programs
  - The New York State Education Department (NYSED)

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Supporting Children as They Develop

4 to 6 years old (Early Childhood)

Developmental challenges - missing milestones

- Doesn't show a wide range of emotions
- Shows extreme behavior (unusually fearful, aggressive, shy or sad)
- Unusually withdrawn and not active
- Easily distracted, has trouble focusing on one activity for more than 5 minutes
- Doesn't respond to people, or responds only superficially
- Can't tell what's real and what's make-believe
- Doesn't play a variety of games and activities
- Can't give first and last name
- Doesn't use plurals or past tense properly
- Doesn't talk about daily activities or experiences
- Doesn't draw pictures
- Can't brush teeth, wash and dry hands, or get undressed without help
- Loses skills they once had

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Supporting Children as They Develop

4 to 6 years old (Early Childhood)

- Changing family expectations & concerns
  - Safety- each DD/IDD poses its' own set of challenges
  - Self care challenges- activities of daily living (ADL) skills (i.e. bathing, toileting, oral care, eating skills)
  - Schedules - support services not always available evenings/weekends
- Services available-see resource list
  - NYSED, Office for People With Developmental Disabilities (OPWDD) OPWDD Developmental Disabilities Regional Offices (DDRO) – Family Support Services (FSS), respite, community habilitation, self direction 5 years and older

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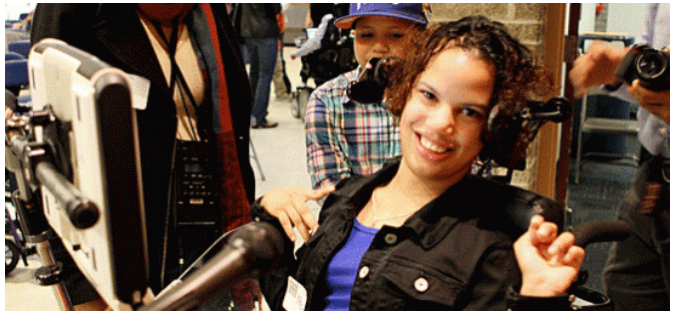
Supporting Children as They Develop

6 to 10 years old (Middle Childhood)

- Changing family expectations
  - Adolescents experience - hormonal changes, exploring boundaries, fitting in, self acceptance,
  - Social challenges – supportive environment, discrimination, bullying
- Services available
  - The New York State Education Department (NYSED)



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Supporting Children as They Develop

11 to 20 years old

- Developmental challenges
  - Delayed physical growth
  - Addition of hormonal changes
  - Exploration of sexuality
- Changing family expectations & challenges
  - Transition planning services part of Individualized Education Plan (IEP)
  - Circle of support
  - Supportive decision making
  - Educational and Vocational supports & options
  - Long Term Planning
- Services available-
  - Best Buddies program
  - OPWDD Family Support Services, respite, after school, behavioral supports

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Engaging Children with I/DD and their Families

Parents and families need education and support

- Understanding developmental challenges
  - How are they handling changes in expectations?
    - Counseling, support groups
    - A break (respite services)
    - Fun
- Must meet the family "where they are"
  - Multicultural & diverse
  - Multiple & singular
  - Family centered
- Decision-making about services and understanding options
  - Gather resources
  - Make informed decisions
  - Choice based on needs of all family members
- Advocating for their child in every way possible

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Supporting Children with I/DD who are Medically Fragile

Definition of Medically Fragile:

- Chronic debilitating conditions
  - Ex. Bronchopulmonary dysplasia, cerebral palsy, congenital heart disease, microcephaly, pulmonary hypertension and muscular dystrophy
- May or may not require hospitalization/ institutionalization
- One or more of the following
  - Dependent on technology for life or health sustaining functions
  - Requires complex medication regimen or medical interventions to maintain or improve health
  - In need of ongoing assessment or intervention to prevent serious deterioration of health or medical complications

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Supporting Children with I/DD who are Medically Fragile

Special Considerations

- Complex healthcare needs → interacting with multiple providers/services
- Comprehensive coordination of care among medical professionals, teachers and family
- Stress and fear can look like acting out or regression
- Be aware of common fears of medically fragile children at different ages
- Outpatient services may be interrupted by more frequent hospitalizations

Supports Available

- Medicaid Managed Care Liaison for Medically Fragile Children
- Child Life Specialist
- Palliative care

Retrieved from: https://www.naeyc.org/resources/pubs/yc/sep2017/supporting-medically-fragile-children

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Supporting Children with I/DD Who Are in Foster Care

- Approximately 60 percent of children in care have a chronic medical condition
- 25 percent have 3 or more chronic problems.
- Approximately 60 percent of preschoolers have developmental delays
- Children in foster care use both inpatient and outpatient mental health services at a rate 15 to 20 times higher than the general pediatric population.
- Between 40 percent and 60 percent of children in foster care have at least one psychiatric disorder.
- Children in foster care experience higher rates of physical and emotional problems than those in the general population

Retrieved from: https://ocfs.ny.gov/main/

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Supporting Children with I/DD who are in Foster Care

Special Considerations

- High touch
- Complex health and behavioral health needs
- Likelihood of trauma - requires trauma informed care
  - Complex Trauma
- Potential for more periods of transition/movement between settings which could exacerbate conditions
- Variety of foster care experiences (i.e. temporarily removed from home and placed in Voluntary Foster Care Agency, long-term foster parents, etc.)

Supports Available

- OCFS
- Medicaid Managed Care Foster Care Liaison

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Best Practice & Supports to Minimize Challenges

- Early intervention
- Trauma Informed approach
- Seamless supports
- Community Integration
- Positive Behavioral Supports & Approaches
- Technology
- Alternative Approaches
- Respite

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Effect of Children's System Transformation on I/DD Medically Fragile and I/DD in Foster Care

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Children's System Transformation

Goals of Transformation

- Meet the needs of children with physical, emotional and developmental disabilities - including children in foster care and children who are medically fragile
- Better health outcomes for children and youth - resulting in better health in adulthood
- All Medicaid eligible children who meet medical necessity will be able to access CFTSS to meet behavioral health needs
  - Other Licensed Practitioners (OLP)
  - Crisis Intervention
  - Community Psychiatric Support and Treatment (CPST)
  - Psychosocial Rehabilitation Services
  - Family Peer Support Services
  - Youth Peer Support Services

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Impacts on Children and Families Transitioning to Managed Care

What are some of the concerns families of youth with I/DD may have?

- Another component to navigate
- May limit provider options, as are sometimes seeing specialists

How children and families will be affected:

- System in transition
- Holistic approach to support
- More options in service providers

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Medically Fragile Children and Managed Care Plans

Special considerations for Medically Fragile children/Medically Fragile children with I/DD:

- Plans must approve out of network providers if there are no in-network providers to address the needs of the child
- Plans must contract with providers with demonstrated expertise caring for Medically Fragile populations
- Medical Necessity determinations must take into account the specific needs of the child and their circumstances
- Plans need to accommodate unique stabilization needs and discharge delays
- For more information about this, see the Medicaid Managed Care Model Contract

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Foster Care and Managed Care Plans

Special considerations for children in Foster Care/children with I/DD in Foster Care:

- Children entering or being discharged from Foster Care may change plans during intake, placement, or discharge planning
- If child is disenrolling, plan must create discharge plan to ensure continuity of care
- Health requirements for Foster Children – specified in 18 NYCRR § 441.22 and Part 507
  - Includes thirty (30) day obligations for a comprehensive physical and behavioral health assessment and assessment of the risk that the child may be HIV+ and should be tested
- Plans must coordinate care with local government units (LDSS) responsible for Foster Care
- For more information about this, see the Medicaid Managed Care Model Contract

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System Transformation: New/Adapted Services for I/DD who are Medically Fragile and/or I/DD in Foster Care

As part of Children's System Transformation:

- Children's HCBS: children who are Medically Fragile* with a Developmental Disability and children with a Developmental Disability in Foster Care meet LOC eligibility for Children's HCBS
  - The Children's HCBS array of services aims to improve the health and well-being of these children and avoid, delay, or prevent medical institutional care
  - Some of these children may have been receiving similar services through waivers that transitioned to Children's HCBS
- **More information about the specifics of HCBS in other presentations.**

*Medically Fragile: for the purposes of Children's HCBS, a "medically fragile child" is defined as an individual who is under 21 years of age whose target population, risk factors, and functional criteria align with the Medically Fragile or Medically Fragile and DD LOC criteria (more information on this in resources).

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System Transformation: New/Adapted Services for I/DD who are Medically Fragile and/or I/DD in Foster Care

- Health Home Care Management:
  - Children with Developmental Disabilities are eligible to receive OPWDD Care Coordination/Health Home (CCO/HH) https://opwdd.ny.gov/opwdd_services_supports/care_coordination_organizations/CCOs
  - Children who are Medically Fragile with a Developmental Disability and children with a Developmental Disability in Foster Care are eligible for Health Home Care Coordination

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Overview of Services Available to Health Home Serving Children and Care Coordination Organization/Health Home Enrollees

Health Home Serving Children Program	Care Coordination Organization/Health Home (CCO/HH)
For children under 21 who meet eligibility/chronic conditions criteria	For individuals who have Intellectual and/or Developmental Disabilities (I/DD) of any age who are eligible for OPWDD services
Health Homes provide the following Care Coordination Services:	CCO/HH provide the following Care Coordination Services:
Comprehensive Care Management - assess needs, develop care plan **Care Coordination and Health Promotion - work with providers** **Comprehensive Transitional Care - discharge planning, help to new programs** **Enrollee and Family Support - assist with appointments and meetings** **Referral to Community and Social Supports - link to services and resources**	
Consolidated 1915(c) Children's Waiver, enrollees who also meet Home and Community Based Services (HCBS) eligibility will also be able to receive (as appropriate) full array of HCBS.	CCO/HH will coordinate the services for CCO/HH enrollees who are enrolled in the OPWDD Comprehensive Waiver.

Remember, regardless of their circumstance….

All Children

- Learn
- Change
- Grow
- Have gifts, capacities and dreams
- Express preferences, needs, wants and emotions

Even if some don't or can't use words to communicate,

ALL BEHAVIOR IS COMMUNICATION!!

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Resources

- Office for People With Developmental Disabilities (OPWDD) https://opwdd.ny.gov/
- Center for Disease Control and Prevention(CDC) https://www.cdc.gov/
- Center for Parent Information and Resources https://www.parentcenterhub.org/
- New York State Education Department http://www.nysed.gov/
- National Association for the Education of young children (naeyc) https://www.naeyc.org/
- Parent to Parent of NYS http://parenttoparentnys.org/
- Office for Children and Families (OCFS NY) https://ocfs.ny.gov/main/

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Appendix

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Level of Care (LOC) HCBS Eligibility Determination Criteria: Developmental Disability and Medically Fragile Child
***NOTE: Children who qualify as both DD and MFC may more expeditiously access HBCS services by using the Medically Fragile process and then at a later date pursue DD eligibility**

Target Criteria DD MFC	1. Age 0 through child's 21st Birthday, and 2. Child has developmental disability as defined by OPWDD which meets one of the criteria a-c as well as criteria d and e. a. is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment or autism; or b. is attributable to any other condition found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior with mental retardation or requires treatment and services similar to those required for such children; or c. is attributable to dyslexia resulting from a disability described above; and d. has continued or can be expected to continue indefinitely; and e. constitutes a substantial handicap to such child's ability to function normally in society.
Risk Factors DD MFC	The child must be Medically fragile as demonstrated by a licensed practitioner of the healing arts (LPHA), who has the ability to diagnose within his/her scope of practice under State law, has determined in writing, that the child, in the absence of HCBS, is at risk of institutionalization (i.e., hospitalization or nursing facility) The LPHA has submitted written clinical documentation to support the determination
Functional Criteria DD MFC	Algorithm applied to a subset of questions from the Child and Adolescent Needs and Strengths New York (CANS-NY) or Office for People with Developmental Disabilities (OPWDD) Level of Care using the ICF-IDD LOC eligibility tool
Financial Criteria DD MFC	If a child is already Medicaid eligible, then a child meeting LOC MFC target criteria, risk factors, and functional criteria is eligible to receive HCBS. If a child is not already eligible for Medicaid and qualifies under no community eligibility rules, then a child meeting LOC MFC target criteria, risk factors, and functional criteria can be considered for Medicaid eligibility under the Family of One financial criteria. Note: Children with DD and not meeting these target criteria and risk factors would be served by the OPWDD HCBS delivery system.

Level of Care (LOC) HCBS Eligibility Determination Criteria: Developmental Disability and Foster Care – July 1, 2018

Target Criteria DD Foster Care	1. Age 0 through child's 21st Birthday, and 2. Child has developmental disability as defined by OPWDD which meets one of the criteria a-c as well as criteria d and e. a. is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment or autism; or b. is attributable to any other condition found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior with mental retardation or requires treatment and services similar to those required for such children; or c. is attributable to dyslexia resulting from a disability described above; and d. has continued or can be expected to continue indefinitely; and e. constitutes a substantial handicap to such child's ability to function normally in society.
Risk Factors DD Foster Care	The child must meet either criteria 1 or 2 1. a current Foster Care (FC) child in the care and custody of Local Departments of Social Services (counties and New York City) (LDSS) or a child in the custody of OCFS Division of Juvenile Justice and Opportunities for Youth (DJJOY) or 2. a FC child who enrolled in HCBS originally while in the care and custody (LDSS) or (DJJOY). Once enrolled, eligibility can continue after the child is discharged from LDSS and OCFS DJJOY custody so long as the child continues to meet targeting, risk and functional criteria (no break in coverage permitted). This risk factor continues Maintenance of Effort for children up through, but not including, their 21st birthday).
Functional Criteria DD Foster Care	Office for People with Developmental Disabilities (OPWDD) Level of Care using the ICF-IDD LOC eligibility tool
Financial Criteria DD Foster Care	If a child is already eligible for Medicaid (e.g., currently in the care and custody of LDSS/DJJOY or was formerly in the care and custody of LDSS/DJJOY and is eligibility under community Medicaid eligibility rules), then a child meeting LOC DD FC target criteria, risk factors, and functional criteria is eligible to receive HCBS. If a child is not already eligible for Medicaid and qualifies under no community eligibility rules, then a child meeting DD target criteria, risk factors (either medically frail or formerly in the care and custody of LDSS/DJJOY), and HCBS LOC functional criteria can be considered for Medicaid eligibility under the Family of One financial criteria. Note: Children with DD and not meeting these target criteria and risk factors would be served by the OPWDD HCBS delivery system.

Thank you!

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