Subtle Signs and Symptoms of Illness and Injury

Developmental Disabilities Support Division

Resource Packet A
Introduction

Required for:
RN, LPN, SLP, PT, OT, BSC,
and
Optional for RD/LD/LN and Other

NEW MEXICO
Department of Health
Developmental Disabilities Supports Division

2021

There are no conflicts of interest in the presentation and activities for this training.

This is a free session without sponsorship.

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Online Registration at ____

A DDSD ID# must be established for DDW service providers to receive training credit.

This training will meet the training requirements listed in the 2021 DDW Standards.

Continuing Education Units (CEUs)

Continuing Education Units are pending for:

RN/LPN

OT, PT, SLP

Counseling (LCSW, LMSW, LPCC, LMHC).

Developmental Disabilities Supports Division

Subtle Signs and Symptoms of Illness and Injury

Date: 9/1/2021
Place: Online

Required for:
Nurses, PTs, SLPs, OTs, and BSCs

Optional for:
RD/LD/LN and others who are interested.

NEW MEXICO
Department of Health
Developmental Disabilities Supports Division

Subtle signs of illness or injury may be any change from the individual's usual state or behavior,

Teams face complex challenges to best meet the needs and desires of the individuals they support.

General Objectives:

After this training, the professional clinicians working with adult I/DD individuals will:

1. Be able to identify common health issues experienced by persons with I/DD in New Mexico that cause illness, hospitalizations and deaths.
2. Have an improved understanding of their discipline specific and Team responsibilities in supporting timely identification and communication about health issues and access to care in accord with the individual's wishes.

General Competencies for <u>all participants</u>:

After this training, DDW Clinicians will be able to:

1. Identify typical and subtle signs of illness related to Infection; Aspiration; Dehydration/Malnutrition; Constipation/Bowel Obstruction, Falls/Injury.
2. Identify the actions to be taken by the Interdisciplinary Team (IDT) when typical or subtle signs of illness an injury are reported or noted.
3. Identify behavioral manifestations that could be subtle signs of illness, injury, or pain.
4. Identify key elements that support Person Centered Planning and informed Decision Making for Health needs.
5. Identify 3 key actions that support quality Health Care Coordination within the DDW
6. Incorporate critical clinical information into DSP training

Additional Discipline Specific Competencies:

Nurses

After this training, the nurse will be able to:

1. Assess for the indications of Illness and Injury or subtle signs of illness in individuals with I/DD and identify 3 (three) sign and symptoms for each of the "NM fatal 5".
2. Identify 2 (two) behaviors that can increase the risk for illness or injury
3. List 1 (one) complications the following medications could have that will increase the risk for illness and injury
   a. Dilantin
   b. Depakote
   c. Ativan
4. Identify key elements that must be included about subtle signs of illness related to the "NM Fatal 5" when creating health care plans and presenting individual specific training

Physical Therapists (PT)

After this training, the PT will be able to:

1. Identify 2 (two) positioning challenges that could contribute to the risk for illness and injury
2. List 3 (three) body-systems related issues which can cause skin breakdown.
3. Recognize 2 (two) signs and symptoms of mobility-related issues that could increase the risk for illness and injury

Speech-Language Pathologists (SLP)

After this training, the SLP will be able to:

1. Identify 3 (three) interventions to prevent or treat dehydration, aspiration, and constipation.
2. Identify 3 (three) communication interventions that may address presentation of general pain and individual specific symptoms.

Occupational Therapist (OT)

After this training, the OT will be able to:

1. Identify 2 (two) intervention to prevent constipation and dehydration.
2. Describe 2 (two) interventions for fall prevention.

Dietitian (RD, LD, LN)

After this training, the Dietitian will be able to:

1. List 2 (two) foods known as choking hazards.
2. Identify 5 (five) signs of dehydration and/or malnutrition.
3. Determine an individual's fluids needs
4. Describe 2 (two) interventions for prevention of constipation.
5. Identify 2 (two) interventions to help prevent GERD.

Behavioral Support Consultant (BSC)

After this training, the BSC will be able to:

1. Identify 2 (two) behaviors that will contribute to increased risk for illness and injury.
2. Assess behavioral manifestations of illness and pain (both common & atypical) to assist in the determination of the need for medical treatment and/or medication vs. behavioral intervention.
3. Identify 3 (three) potential behavioral interventions that may address presentation of general pain and individual specific symptoms.

NM-DOH

Our mission is to promote health and wellness, improve health outcomes, and assure safety net services for all people in New Mexico.

Developmental Disabilities Supports Division

The Developmental Disabilities Supports Division (DDSD) oversees three home and community-based Medicaid waiver programs. These include the Developmental Disabilities Waiver (Traditional Waiver), the Medically Fragile Waiver (Traditional Waiver), Mi Via Self-Directed Waiver and the Supports Waiver. Our Intake and Eligibility Bureau manages the Central Registry for individuals waiting for services. DDSD also provides several State General Funded Services.

DDSD administers the Family Infant Toddler (FIT) Program, in accordance with the Federal Individuals with Disabilities Education Act (IDEA), for children birth to three years old with or at risk for developmental delay or disability.

DDSD Core Values

Vision

Our vision is for people with intellectual and developmental disabilities to live the lives they prefer in their communities.

Mission

Our mission is to effectively administer a system of person-centered community supports and services that promotes positive outcomes for all stakeholders with a primary focus on assisting individuals with developmental disabilities and their families to exercise their right to make choices, grow and contribute to their community.

Principles

Our guiding principles are as follows.

- Stay Results Focused
- Work for System Simplicity, Accountability, and Transparency
- Stay Person/Family Centered
- Use information wisely using Evidence-Based Practices
- Work in Partnership
- Promote Choice
- Emphasize Prevention

Actions

We will put our guiding principles into action with these basic steps.

- Accountability – Demonstrate honesty, integrity and honor commitments.
- Communication – Promote trust through mutual, honest and open dialogue.
- Teamwork – Share expertise and ideas through creative collaboration to work toward common goals.
- Respect – Appreciate the dignity, knowledge, and contributions of all persons.
- Leadership – Promote growth and lead by example throughout the organization and in communities.
- Customer Service – Place internal and external customers first by assuring their needs are met.

The New Mexico definition per NMAC 8.290.400.7

Adaptive behavior:

The effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected for their age and cultural group.

Developmental disability:

For the purposes of the DD waiver, a developmental disability is limited to an intellectual disability or a specific related condition as defined by the department of health/developmental disabilities supports division (DOH/DDSD) that is likely to continue indefinitely and results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

Developmental period:

The time between birth and the 18th birthday.

Disability determination services unit (DDSU):

The unit that determines disability as described in 8.200.420.11 NMAC.

Intellectual disability:

Refers to significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. Intellectual disability replaces all references to mental retardation.

Developmental disabilities (DD) waiver:

- The developmental disabilities waiver identified as category 096 was approved effective July 1984, subject to renewal. Developmental disabilities waiver services are intended for eligible recipients who have developmental disabilities limited to intellectual disability (IID) or a specific related condition as determined by the DOH/DDSD.
- The developmental disability must reflect the person's need for a combination and sequence of special interdisciplinary or generic treatment or other supports and services that are lifelong or of extended duration and are individually planned and coordinated.
- The eligible recipient must also require the level of care provided in an intermediate care facility for individuals with developmental disabilities (ICF/IID), in accordance with 8.313.2 NMAC, and meet all other applicable financial and non-financial eligibility requirements.
    - *Intellectual disability*:
        - An individual is considered to have MR/ID if she/he has significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.
    - *Specific related condition:*
      An individual is considered to have a specific related condition if she/he has a severe chronic disability, other than mental illness, that meets all of the following conditions:
        - is attributable to:
            - cerebral palsy or seizure disorder; or
            - is attributable to autistic disorder (as described in the fourth edition of the diagnostic and statistical manual of mental disorders); or 8.290.400 NMAC 2
            - is attributable to chromosomal disorders (e.g. down), syndrome disorders, inborn errors of metabolism, or developmental disorders of the brain formation limited to the list below;
        - results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disability and requires treatment or services similar to individuals with ID;
        - is manifested before the person reaches age 22 years;
        - is likely to continue indefinitely; and
        - results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

List of chromosomal disorders

Syndrome disorders, inborn errors of metabolism or developmental disorders of the bring formation.

- Chromosomal disorders:
  - *autosomes*:
    - 4p-, trisomy 4p, trisomy 8, 5p-, 9p-, trisomy 9p, trisomy 9p mosaic, partial trisomy 10q, 13q-, ring 13, trisomy 13 (Patau), 18p-, 18q-, trisomy 18 (Edwards), Ttisomy 20p, G (21,22) monosomy/deletion, trisomy 21 (down), translocation 21 (down), "cat-eye" syndrome; Prader-Willi syndrome (15);
  - *x-linked mental retardation*:
    - Allan syndrome; Atkin syndrome; Davis syndrome; Fitzsimmons syndrome; fragile x syndrome; fragile x phenotype (no fragile site); Gareis syndrome; glycerol kinase deficiency; Golabi syndrome; Homes syndrome; Juberg syndrome; Lujan syndrome; Renpenning syndrome; Schimke syndrome; Vasquez syndrome; nonspecific x-linked mental retardation;
  - *other x chromosome disorders*:
    - xo syndrome (Turner); xyy syndrome; xxy syndrome (Klinefelter); xxyy syndrome; xxxy syndrome; xxxx syndrome; xxxxy syndrome; xxxxx syndrome (penta-x);

- Syndrome disorders:
  - *Neurocutaneous disorders*:
    - ataxia-telangiectasia (Louis-Bar); basal cell nevus syndrome; dyskeratosis congenital; ectodermal dysplasia (hyperhidrotic type); ectromelia ichthyosis syndrome; focal dermal hypoplasia (Goltz); ichthyosis-hypogonadism syndrome, incontinentia pigmenti (BlochSulzberger); Ito syndrome; Klippel-Trenauney syndrome; linear sebaceous nevus syndrome; multiple lentigines syndrome; neurofibromatosis (Type 1); poikiloderma (Rothmund-Thomsen); Pollitt syndrome; Sjogren-Larsen syndrome; Sturge-Weber syndrome; tuberous sclerosis; xeroderma pigmentosum;
  - *Muscular disorders:*
    - Becker muscular dystrophy; chondrodystrophic myotonia (Schwartz-Jampel); congenital muscular dystrophy; Duchenne muscular dystrophy; myotonic muscular dystrophy;
  - *Ocular disorders:*
    - Aniridia-Wilm's tumor syndrome; anophthalmia syndrome (x-linked); Leber amaurosis syndrome; Lowe syndrome; microphthalmia-corneal opacity-spasticity syndrome; Norrie syndrome; oculocerebral syndrome with hypopigmentation; retinal degeneration-trichomegaly syndrome; septo-optic dysplasia;
  - *Craniofacial disorders:*
    - acrocephaly-cleft lip-radial aplasia syndrome; acrocephalosyndactyly;type 1 (Apert); type 2 (Apert); type 3 (Saethre-Chotzen); type 6 (Pfeiffer); Carpenter

syndrome with absent digits and cranial defects; Baller-Gerold syndrome; cephalopolysyndactyly (Greig) "cloverleaf-skull" syndrome; craniofacial dysostosis (Crouzon); craniotelencephalic dysplasia; multiple synostosis syndrome;

- *Skeletal disorders:*
  - acrodysostosis, CHILD syndrome; chondrodysplasia punctata (Conradi-Hunerman type); chondroectodermal dysplasia; Dyggve-Melchior-Clausen syndrome; frontometaphyseal dysplasia; hereditary osteodystrophy (Albright); hyperostosis (Lenz-Majewski); hypochondroplasia; Klippel-Feil syndrome; Nail-patella syndrome; osteopetrosis (Albers-Schonberg); pyknodysostosis; radial aplasia-thrombocytopenia syndrome; radial hypoplasia pancytopenia syndrome (Fanconi); Roberts-SC phocomelia syndrome;

- <u>Inborn errors of metabolism:</u>
  - *Amino acid disorders:*
    - phenylketonuria: phenylalanine hydroxylase (classical, Type 1); dihydropteridine reductase (type 4); dihydrobiopterin synthetase (type 5); histidinemia; gammaglutamylcysteine synthetase deficiency; hyperlysinemia; lysinuric protein intolerance; hyperprolinemia; hydroxyprolinemia; sulfite oxidase deficiency; iminoglycinuria; branched-chain amino acid disorders: hypervalinemia; hyperleucine-isoleucinemia; maple-syrup urine disease; isovaleric academia, glutaric academia (type 2); 3-hydroxy-3-methylglutaryl CoA lyase deficiency; 3-kethothiolase deficiency;,biotin-dependent disorders: holocarboxylase deficiency; biotinidase deficiency; propionic academia: type A; Type BC; methylmalonic 8.290.400 NMAC 3 academia: mutase type (mut+); cofactor affinity type (mut-); adenosylcobalamin synthetase type (cbl A); ATP: cobalamin adenosyltransferase type (cbl B), with homocystinuria, type 1 (cbl C), with homocystinuria, type 2 (cbl D); folate-dependent disorders: congenital defect of folate absorption; dihydrofolate reductase deficiency; methylene tetrahydrofolate reductase deficiency; homocystinuria; hypersarcosinemia; non-ketotic hyperglycinemia; hyper-betaalaninemia; carnosinase deficiency; homocarnosinase deficiency; Hartnup disease; methionine malabsorption (oasthouse urine disease);
  - *Carbohydrate disorders:*
    - glycogen storage disorders: type 1, with hypoglycemia (von Gierke); type 2 (Pompe); galactosemia; fructose-1, 6-diphosphatase deficiency; pyruvic acid disorders: pyruvate dehydrogenase complex (Leigh); pyruvate carboxylase deficiency; mannosidosis; fucosidosis; aspartylglucosaminuria;
  - *Mucopolysaccharide disorders:*
    - alpha-L-iduronidase deficiency: Hurler type; Scheie type, Hurler-Scheie type; iduronate sulfatase deficiency (Hunter type); Heparan N-sulfatase deficiency (Sanfilippo 3A type); N-acetyl-alpha-D-glucosaminidase deficiency (Sanfilippo 3B

type); Acetyl CoA; glucosaminide N-acetyltransferase deficiency (Sanfilippo 3C type); N-acetyl-alpha D-glucosaminide 6-sulfatase deficiency (Sanfilippo 3D type); beta-glucuronidase deficiency (Sly type);

- *Mucolipid disorders:*
  - alpha-neuraminidase deficiency (type1); Nacetylglucosaminyl phosphotransferase deficiency: I-cell disease (Type 2); Pseudo-Hurler syndrome (type 3); mucolipidosis type 4;
- *Urea cycle disorders:*
  - carbamyl phosphate synthetase deficiency; ornithine transcarbamylase deficiency; argininosuccinic acid synthetase deficiency (citrullinemia); argininosuccinic acid (ASA) lyase deficiency; arginase deficiency (argininemia);
- *Nucleic acid disorders:*
  - Lesch-Nyhan syndrome (HGPRTase deficiency); orotic aciduria; xeroderma pigmentosum (group A); DeSanctis-Cacchione syndrome;
- *Copper metabolism disorders:*
  - Wilson disease; Menkes disease;
- *Mitochondrial disorders:*
  - Kearns-Sayre syndrome; MELAS syndrome; MERRF syndrome; cytochrome c oxidase deficiency; other mitochondrial disorders;
  - Peroxisomal disorders:
    - Zellweger syndrome; adrenoleukodystrophy: neonatal (autosomal recessive); childhood (x-linked); infantile Refsum disease; hyperpipecolic academia; chondrodysplasia punctata (rhizomelic type);

- <u>Developmental disorders of brain formation:</u>
  - *Neural tube closure defects:*
    - anencephaly; spina bifida; encephalocele;
  - *Brain formation defects:*
    - Dandy-Walker malformation; holoprosencephaly; hydrocephalus: aqueductal stenosis; congenital x-linked type; Lissencephaly; pachygyria; polymicrogyria; schizencephaly;
  - *Cellular migration defects*:
    - Abnormal layering of cortex; colpocephaly; heterotopias of gray matter; cortical microdysgenesis
  - *Intraneuronal defects:*
    - dendritic spine abnormalities; microtubule abnormalities;
  - Acquired brain defects:
    - Hydranencephaly; porencephaly; and
  - *Primary (idiopathic) microcephaly*.

- Brain injury (BI):
    - Brain injury services are designated as category 092.
    - To qualify for purposes of this waiver, the eligible recipient must be under 65 years of age at the time of approval, meet all other applicable financial and non-financial eligibility requirements, require nursing facility level of care and have a brain injury diagnosis, as defined by the state.
    - *Brain injury is defined as:*
        - an injury to the brain of traumatic or acquired origin including:
            - open and closed head injuries caused by an insult to the brain from an outside physical force;
            - anoxia,
            - electrical shock,
            - shaken baby syndrome,
            - toxic and chemical substances,
            - near-drowning,
            - infections; tumors, or
            - vascular lesions;
        - resulting in either temporary or permanent, partial or total impairments in one or more areas including, but not limited to:
            - cognition; language; memory; attention; reasoning;
            - abstract thinking; judgment; problem solving;
            - sensory perception and motor abilities;
            - psychosocial behavior; physical functions;
            - information processing; and speech resulting in total or partial functional disability or psychosocial impairment or both;
        - the term “brain injury” does not apply to injuries that are
            - congenital,
            - degenerative,
            - induced by birth trauma or
            - neurological disorders related to the aging process, or
            - chemically caused brain injuries that are a result of habitual substance abuse.

Additional IDD Information

Disorders may also classified as:

1. **Genetic**
   - result from abnormalities of genes inherited from parents,
   - errors when genes combine, or
   - other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors.
   - There are many genetic diseases associated with intellectual disability
   - Range from minuscule to major
2. **Metabolic**
   - There are hundreds of different genetic metabolic disorders, and their symptoms, treatments, and prognoses vary widely.
   - There are hundreds of inherited metabolic disorders, caused by different genetic defects. Examples include:
     - Familial hypercholesterolemia
     - Gaucher disease (bone pain, enlarge liver, low plts)
     - Hunter syndrome
     - Krabbe disease (progressive nerve damage)
     - Maple syrup urine disease (buildup of amino acids)
     - Metachromatic leukodystrophy
     - Mitochondrial encephalopathy, lactic acidosis, stroke-like episodes (MELAS)
     - Niemann-Pick *(liver enlargement, difficulty feeding, nerve damage)*
     - Phenylketonuria (PKU) *(high levels of phenylalanine in blood-mental disability)*
     - Porphyria
     - Tay-Sachs disease *(progressive weakness to severe nerve damage)*
     - Wilson's disease
     - Glycogen storage disease *(low blood sugars, muscle pain, and weakness)* *https://www.mayoclinic.org/diseases-conditions/inherited-metabolic-disorders/symptoms-causes/syc-20352590*
3. **Acquired**
   - *During pregnancy*
     - *Alcohol and drug use by the mother*
     - *Smoking*
     - *Malnutrition*
     - *Environmental toxins*
     - *Toxoplasmosis,*
     - *cytomegalovirus,*
     - rubella and
     - syphilis
   - *During Birth*
     - Prematurity and low birth weight
     - Temporary Oxygen deprivation

        - Birth injuries (The Arc, 2017)
    - *<u>After birth</u>*
        - *Childhood diseases*
            - *whooping cough, chicken pox, measles, and*
            - *Hib disease that may lead to meningitis and encephalitis*
        - *Trauma, abuse or accidents such as shaken baby syndrome, near drowning or car accidents*
        - *Stroke*
        - *Hemorrhage*
        - *Anoxia*
        - *Infections (Zika)*
        - Toxic exposure
        - Hydrocephalus
        - Tumors (Powell River brain injury society, 2015)

4. **Progressive**
    - Dementia and Alzheimer's disease are seen in people with I/DD. Alzheimer's is commonly seen in people with Down Syndrome.

5. **Mental Health**
    - *Mood disorders*
        - *Depression, bi-polar, and mania*
    - *Anxiety disorders*
        - *Panic attack, agoraphobia, obsessive-compulsive, and PTSD*
    - *Psychotic disorders*
        - *Schizophrenia, schizoaffective disorder, and schizophreniform*
    - *Personality disorders*
        - *Paranoid, anti-social, borderline and avoidant*
    - *Adjustment disorders*
        - *These disorders is the development of clinically significant emotional or behavioral symptoms in response to an identifiable psychosocial stressor*
            - *Adjustment disorder with depressed mood, with anxiety, with disturbance of conduct and with mixed disturbance of emotions and conduct*

6. *Other*
    - *somatoform disorders, factitious disorders, dissociative disorders, sexual and gender identity disorders, eating disorders, sleep disorders, substance abuse related disorders, impulse control disorders, dementia, and dissociative disorders* (NADD, 2017)

When assessing the "Whys" of subtle signs, always start with the medical/biological, particularly when there are language deficits suspected or confirmed.

- Physiological (Hunger, Thirst, Pain)
- Medical (Dental, Seizures, Apnea, IBS, Hypoglycemia)
- Medication (Side Effects)
- Biological (Genetics – Behavioral Phenotypes)
- Psychiatric / Emotional / Behavioral (internal / psychoses)
- Sensory (Repetitive Behavior patterns including Self-Stimulation)
- Communication (Expressive / Receptive)
- Developmental Delay
    - Cognitive / Executive Functioning Deficits (Processing)
- Communication (Expressive / Receptive)
- Trauma
- Environment (including caregiver interactions)
- Social Skills Deficits
- Attention (gaining access to preferred items)
- Escape Avoidance (unpleasant situations / experiences)

Assessment of Trauma

- What is trauma?
    - Reaction thought to result from single event, series of events or set of circumstances that:
        - the individual experiences as physically or emotionally harmful or threatening and
        - has lasting adverse effects on the individual's functioning and
        - physical, social, emotional, or spiritual well-being
    - Can affect any or all --individuals, families, groups, cultures, generations
    - Generally, overwhelms individual's or community's coping resources
    - Often causes 'fight, flight, or freeze' reaction at the time, & frequently produces sense of fear, vulnerability, helplessness long-term
    - Individuals with I/DD experience a greater number of traumatic events in their lives, and ***often have greater difficulty reporting and coping with them***.
    - It is ***imperative*** to talk to familiar caregivers (***more than one if possible!***) about how someone communicates and what they see that is different

- Definition changed over time – narrow definition in only certain circumstances or occupations – too much broader understanding of trauma
- Substance Abuse and Mental Health Services Administration. (2012). *SAMHSA's working definition of trauma and principles and guidance for a trauma-informed approach* [Draft]. Rockville, MD: Substance Abuse and Mental Health Services Administration.
- SAMHSA (2014). A Treatment Improvement Protocol: Trauma-Informed Care in Behavioral Health Services TIP 57