

Importance of Early Identification of Children who are Deaf with Additional Disabilities

National Center on Deaf-Blindness

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DEAF-BLIND NETWORK
TECHNICAL ASSISTANCE ACROSS THE NATION



Outcomes

Increased Awareness and Knowledge of:

- Risk factors associated with combined vision and hearing loss
- Impact of combined vision and hearing loss on early development
- Key evidence-based practices to improve developmental outcomes

Deaf-blindness Defined

1 of 2

- “Deaf-blind” describes any combined hearing and vision loss that significantly limits the ability to get information from people and objects around them.
- These losses can cause developmental delays in all areas of development including language, social skills, and mobility, but they do not necessarily limit the individual’s learning potential.

Deaf-blindness Defined

2 of 2

- Very few individuals identified as deaf-blind are totally deaf and totally blind
- Sensory losses range from mild to completely blind or deaf- the significance is the *combination*

Terms Used to Describe Eligible Children

- Children with combined vision and hearing loss
- Children with deaf-blindness
- Child who is deaf-blind
- Child with dual sensory loss

Deaf-blind Census

- Census information (without names or identifying information) is submitted annually to the US Department of Education
- Assists with funding and planning technical assistance to meet the needs of children
- [2017 Deaf-blind Child Count Report](#)

Prevalence of Deaf-blindness

- Deaf-blindness is an extremely low incidence disability.
- 10,000 children and youth with deaf-blindness in the United States.
- There are approximately 45 children and youth with deaf-blindness in Puerto Rico.

Puerto Rico Deaf-blind Child Count

- Top 3 Etiologies:
 - Complications from Prematurity
 - Hydrocephalus
 - Dandy Walker Syndrome
- Primary Classification of Vision:
 - Low Vision
- Primary Classification of Hearing:
 - Profound Hearing Loss
- 29/45 Children (65%) have one or more additional disability

Co-Occurring Disabilities

- Approximately 90% of children with deaf-blindness have one or more additional disabilities or health problems; 75% have two or more; 50% have three or more.
- For children with complex needs, hearing and vision loss may not yet be recognized or addressed.

Identifying Children with Deaf-blindness

- How do we identify infants and toddlers with combined vision and hearing loss?
 - Know the risk factors
 - Review of medical records
 - Information from parents and caregivers
 - Observation and Screening
 - Follow Up Evaluations

Primary Etiologies for Deaf-blindness

- Hereditary Syndrome Disorders
- Prematurity & Birth Complications
- Infections (Cytomegalovirus, Meningitis, etc...)
- Injury or Stroke

Heredity Syndromes and Disorders

- CHARGE Syndrome
- Down Syndrome
- Trisomy 13
- Usher Syndrome
- Alstrom, Goldenhar, Hurler, Norrie, Cornelia de Lange, Waardenburg

Prenatal History

- History of Maternal Infection during pregnancy
 - CMV (Cytomegalovirus)
 - Toxoplasmosis
 - Herpes
 - Rubella
 - Syphilis
 - Zika

- Prenatal infant exposure to drugs or alcohol

Perinatal Conditions (Check Birth History)

- Low Apgar Scores
 - 1-4 at 1 minute
 - 0-6 at 5 minutes

- Hyperbilirubinemia (jaundice) requiring transfusion

- Mechanical for longer than 5 days

- Premature birth

Prematurity

- Birth weight < 1500 grams (3.3 pounds)
- Retinopathy of prematurity (ROP)
- Preterm birth, exposed to oxygen
- On ventilator longer than 5 days
- Elevated bilirubin requiring transfusion

Postnatal Conditions

1 of 2

- Syndrome associated with hearing loss and/or visual impairment
- Meningitis or encephalitis
- Hydrocephalus/Hydrocephaly
- Cerebral Palsy or other neurological conditions

Postnatal Conditions

2 of 2

- Brain disorders, brain tumors, or malformations of the brain
- Loss of oxygen to the brain
- Severe head trauma
- Prolonged fever
- Child received mycin or other known ototoxic medications (antibiotics directly after birth)

“Red Flag” Terms

■ Anoxia, asphyxia,
hypoxia

■ Atresia

■ Cerebral
hemorrhage

■ Cerebral Palsy

■ Ischemia

■ Meningitis

■ Periventricular
Damage

■ Fetal Alcohol
Syndrome

Red Flag Comments

1 of 2

- “Sometimes she seems to see things, other times she doesn’t.”
- “She has a syndrome called CHARGE, but the eye doctor said her vision is fine.”
- “He spent two months in the NICU and his records say he lost oxygen at birth.”

Red Flag Comments

2 of 2

- “This child has cortical visual impairment as a result of head trauma when she was a baby, but there is nothing in her records about a hearing impairment.”
- “This boy has a syndrome that I’ve never heard of.”

Signs and Symptoms

■ Appearance

- Abnormalities of shape or structure of the eyes or ears
- Atypical formation of face, head, or neck

■ Behaviors

- Atypical listening or vocalizing
- Unusual eye movements, gaze or head position
- Difficulty tracking, reaching, responding

Early Intervention

- Early years are critical for children especially in the areas of social-emotional, cognitive, and communication development.
- Early Intervention services can help families understand their child's sensory impairment(s) and learn how they can support their child's growth and development.

Early Identification and Referral

- DO NOT “Wait and See.” It is recommended that children with one diagnosed sensory impairment (hearing or vision) be evaluated in the other area.
- Referrals to medical and educational services should be made in a timely manner.
- How to refer a child to the [Puerto Rico Deaf-Blind Project](#)

Impacts of Hearing Loss

- Communication challenges
- Hearing may be inconsistent
- Missing or distorted information
- Fatigue, ability to focus
- Difference in how everyday activities are experienced

Impacts of Vision Loss

- Bonding Challenges
- Apprehension
- Missing, inconsistent or distorted information
- Fatigue, inability to focus
- Body and Space Awareness
- Difference in how everyday activities are experienced

Impacts of Deaf-blindness

Deaf-blindness is often described as a disability of
ACCESS

■ Combined Vision and Hearing Loss Affects:

- Communication
- Exploration > Mobility > Engagement > Participation
- Relationships > Social Interaction > Friendships
- Visual & Mental Memory > Concept Development
- Independence
- Incidental Learning

Division for Early Childhood Recommended Practices

- Individuals providing services to children with sensory impairments must have access to training
- The [Sooner the Better Framework](#) created by the National Center on Deaf-blindness
 - Training content in the area of deaf-blindness that is aligned with recommended practices linked to the [Division for Early Childhood \(DEC\) Recommended Practices](#)

How Do Infants and Toddlers Learn?

Early Childhood Development Basics:

- Sensory Exploration
- Movement
- Watching and Listening
- Trying New Things
- Repeating Favorite Activities
- Asking Questions
- Security of Safe, Familiar Environment

Children with Deaf-blindness Learn Differently

Traditional Learners

- Learn most information incidentally- just by seeing and listening to what goes on around them.

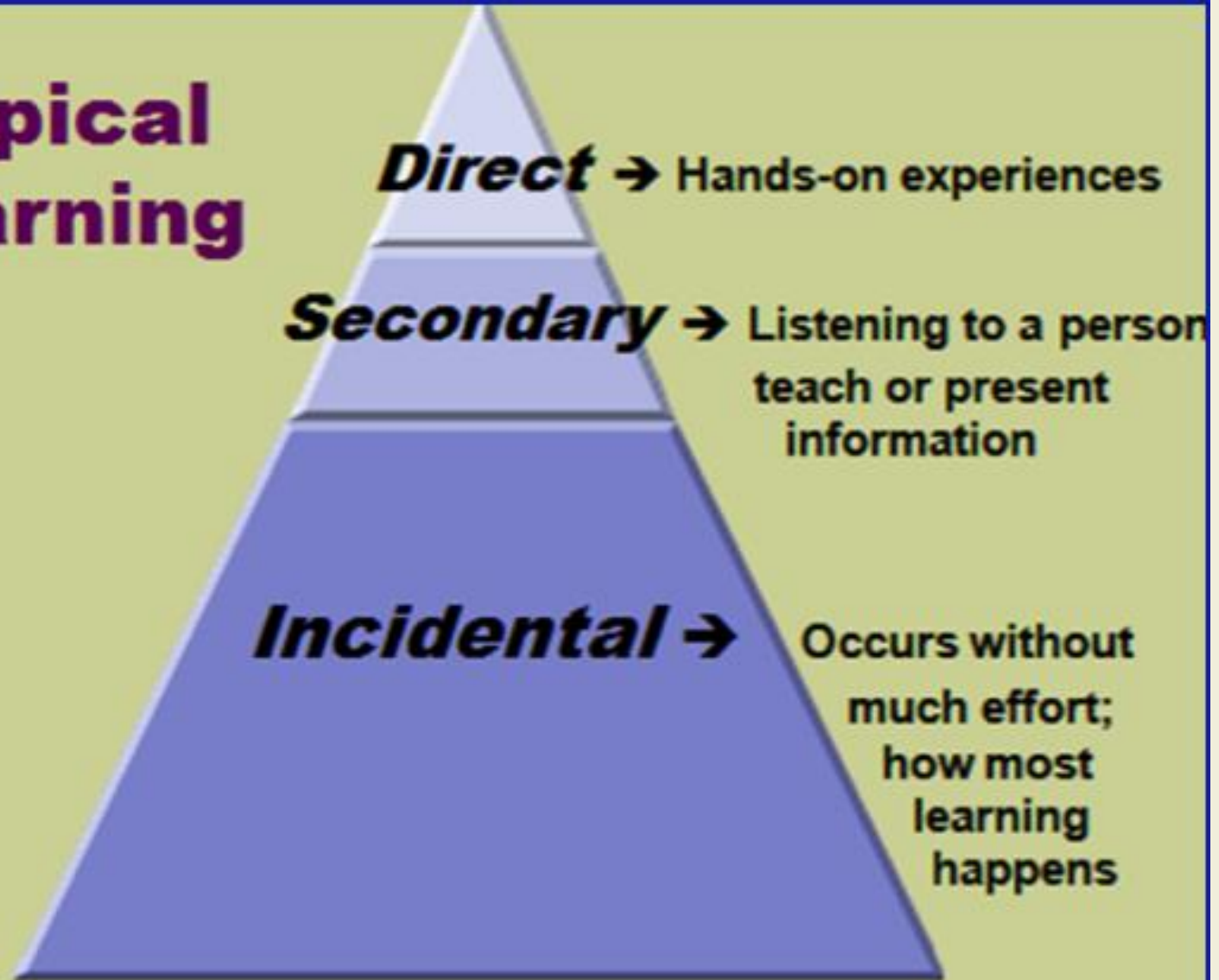
Deaf-Blind Learners

- Incidental learning is challenging and requires careful planning
- Hands-on experience and systematic instruction is essential to learning

Incidental Learning

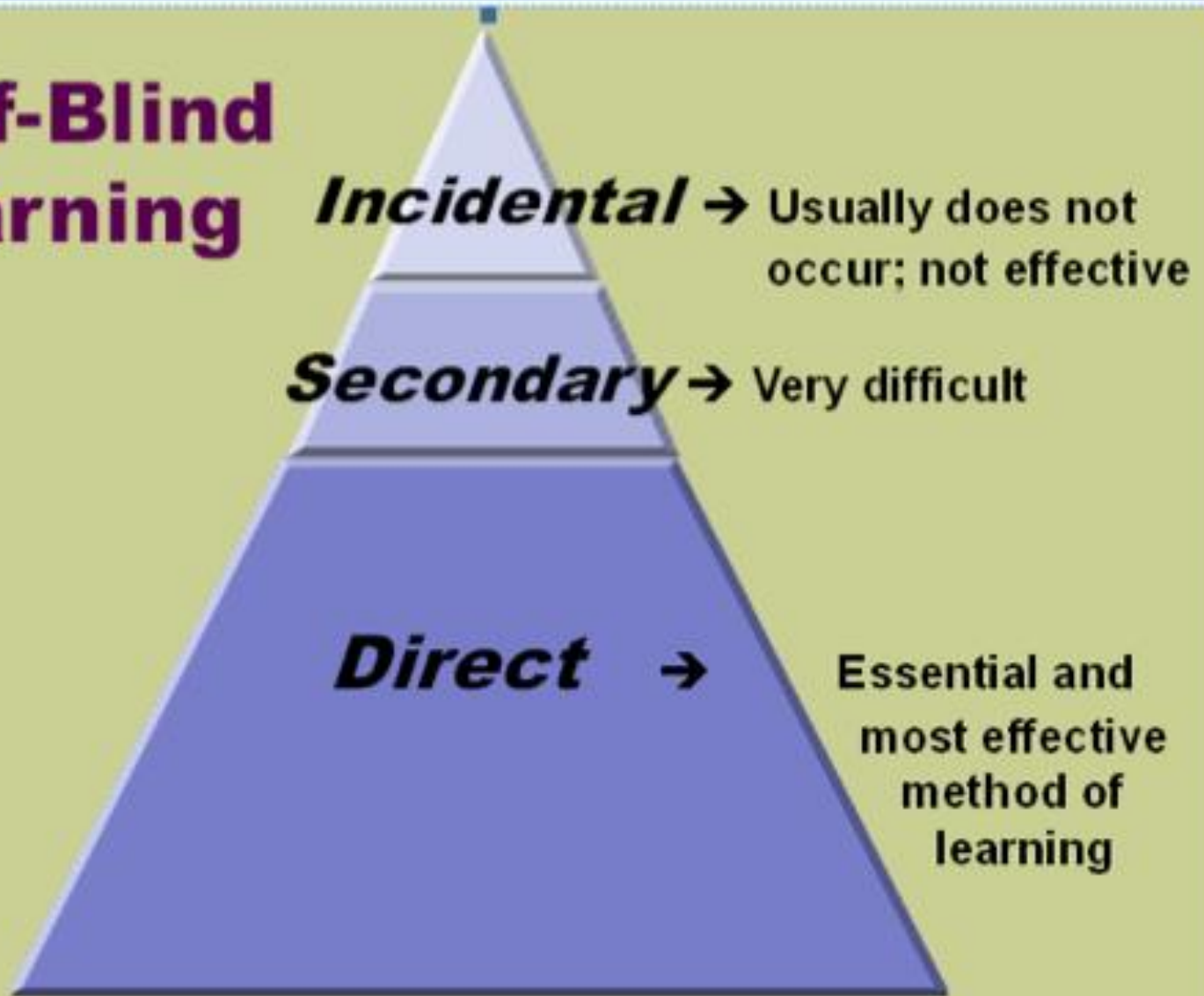
- Occurs as young children watch, listen, and put meaning to what is going on around them
- ***Vision*** and ***Hearing*** are the primary senses for learning
- They are also known as the ***distance senses***

Typical Learning



Alsop, L., 2009

Deaf-Blind Learning



Alsop, L., 2009

Infants and Toddlers with Complex Needs Learn By...

- Touching, tasting, smelling, reaching, moving
- Repeating things they like and avoiding things they don't like
- Asking questions
- Having the opportunity to try
- Being surrounded by people who provide a safe place to learn

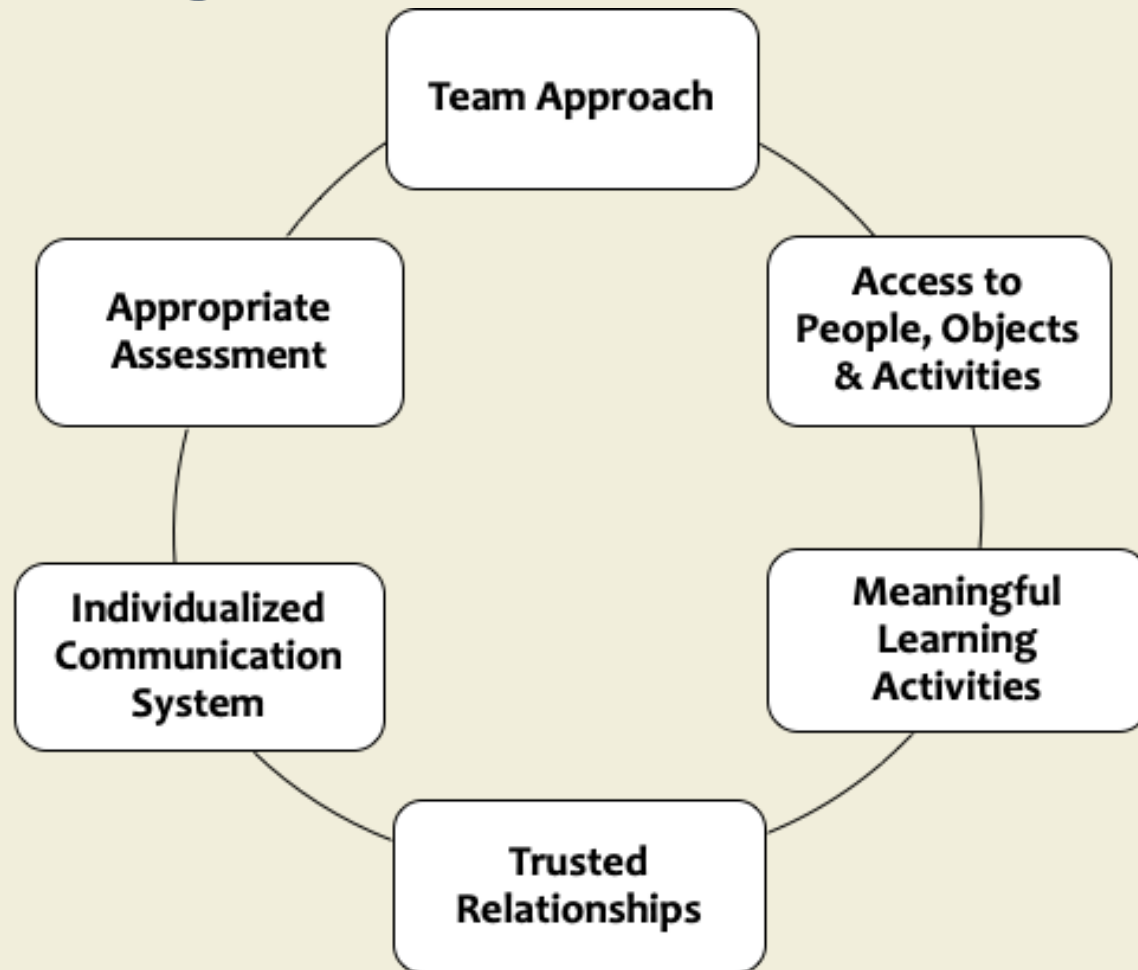
Learning Needs of Children Who Are Deaf-Blind

- Hands-on experiences
- Active movement and exploration of their environment
- Predictable, accessible schedules, consistency
- Use of residual hearing and sight
- High expectations
- Trusting relationships
- Communication, communication, communication

Resource: Overview on Deaf-blindness

- [Learning Module: Overview on Deaf-Blindness and Instructional Strategies](#)

Building a Foundation for Learning



Team Approach

- Parents provide critical input
- Collaboration is key
- Finding what works requires willingness to move out of our typical roles and comfort zones
- Collaborative Teaming and Family Partnership Learning Module
 - Colaboración en equipo y alianzas familiares

Authentic Assessment

- Familiar People
- In familiar settings
- With familiar objects/toys
- Doing familiar things

Adapted from: Sophie Hubbell, M.A.T
Kent State University

Assessment for Children with Deaf-blindness

- Multi-faceted approach
- Functional Vision Assessment (FVA)
- Functional Hearing Assessment (FHA)
- Identifying Sensory Preferences
- Putting the Pieces Together

Assessment Resources

- [Assessing Communication and Learning in Children who are Deafblind or Who Have Multiple Disabilities](#)
- [HomeTalk: A Family Assessment of Children Who are Deafblind](#)
 - [En Español](#)
- [Psychological Evaluation of Children who are Deaf-Blind: An Overview with Recommendations for Practice](#)

Access

- Vision and hearing = Distance Senses
- Multiple Disabilities affect ability to seek information
- Information and responses are absent, limited, or distorted
- Impacts incidental learning

Providing Access

- Maximize residual vision and hearing using functional vision and hearing results
- Provide visual and auditory accommodations
- Ensure proper positioning of child and materials
- Provide time for processing, response, and rest

Resources on Access for Children who are Deaf-blind

- [Learning Module: Maximizing Vision and Hearing](#)
 - [Maximizar la visión y la audición](#)

Respectful Touch

1 of 2

- Hands convey information through
 - Temperature
 - Tone
 - Speed of movement
 - Degree of Pressure

- Children are able to read what is being conveyed through touch

Respectful Touch

2 of 2

- What can you learn about a child from his or her response to your touch?
- What can you learn about a child from his or her reactions to other types of tactile input?
- What do your hands convey when you touch a child?
- Where and how will you touch a child to be most respectful?

Resources: Respectful Touch

- [Learning Module: Touch for Connecting and Learning](#)
 - [El tacto para vincularse y aprender](#)
- [Reflections on Deafblindness: Hands and Touch](#)
- [Talking the Language of the Hands to the Hands](#)
 - [En Español](#)

Communication

All Children Communicate!

Our Role:

- Expectation
- Opportunity
- Interpret and Respond
- Shape
- Model and Coach

Reading Infant Signals

- Communication begins at birth
- May be atypical
- Recognize subtle signs
- Learn to read and respond to each child's unique signals



Communication Systems

- Recognize behavior as communication
- Know hierarchy of communication
- Engage in non-traditional conversations
- Assess receptive and expressive communication modes
- Identify child preferences and interests

Communication Resources

- Assessing Communication: [The Communication Matrix](#)
 - [En Español](#)
- [Learning Module: Understanding Communication Principles](#) (English)
 - [Comprension de los principios de comunicacion](#)
- [Spanish Webinar Series: Comunicación](#)

Meaningful Activities

- Limitations for children with disabilities
 - Range and variety of experiences
 - The ability to move in the environment and community
 - Interaction with the environment

- Overcoming Limitations
 - best intervened through the use of repeated, meaningful, hands on experiences through daily activities with family members.

Berthold Lowenfeld

Routines Based Early Intervention 1 of 2

- Builds on activity settings and learning opportunities
- Promotes child participation in activity settings that have development enhancing qualities
- Based on adult responsiveness to the child

Routines Based Early Intervention 2 of 2

- Takes place in family context
- Takes place in community life
- Takes place wherever the child is with his or her family/caregivers

Considerations for Routines Based Intervention

■ Activity settings and Learning Opportunities

- Not only about how many
- About consistency, relevance, perspective

■ Child Participation

- Not about participation for participation's sake
- About relevance and quality of engagement from the child/family perspective

■ Adult Responsiveness

- Can't always be about what adults want
- About careful observation, slowing down, making activities relevant, meaningful, and fun!

The Importance of Routines

- Predictable
- Provide security
- Decrease stress
- Give opportunities to anticipate
- Give child and family a sense of control

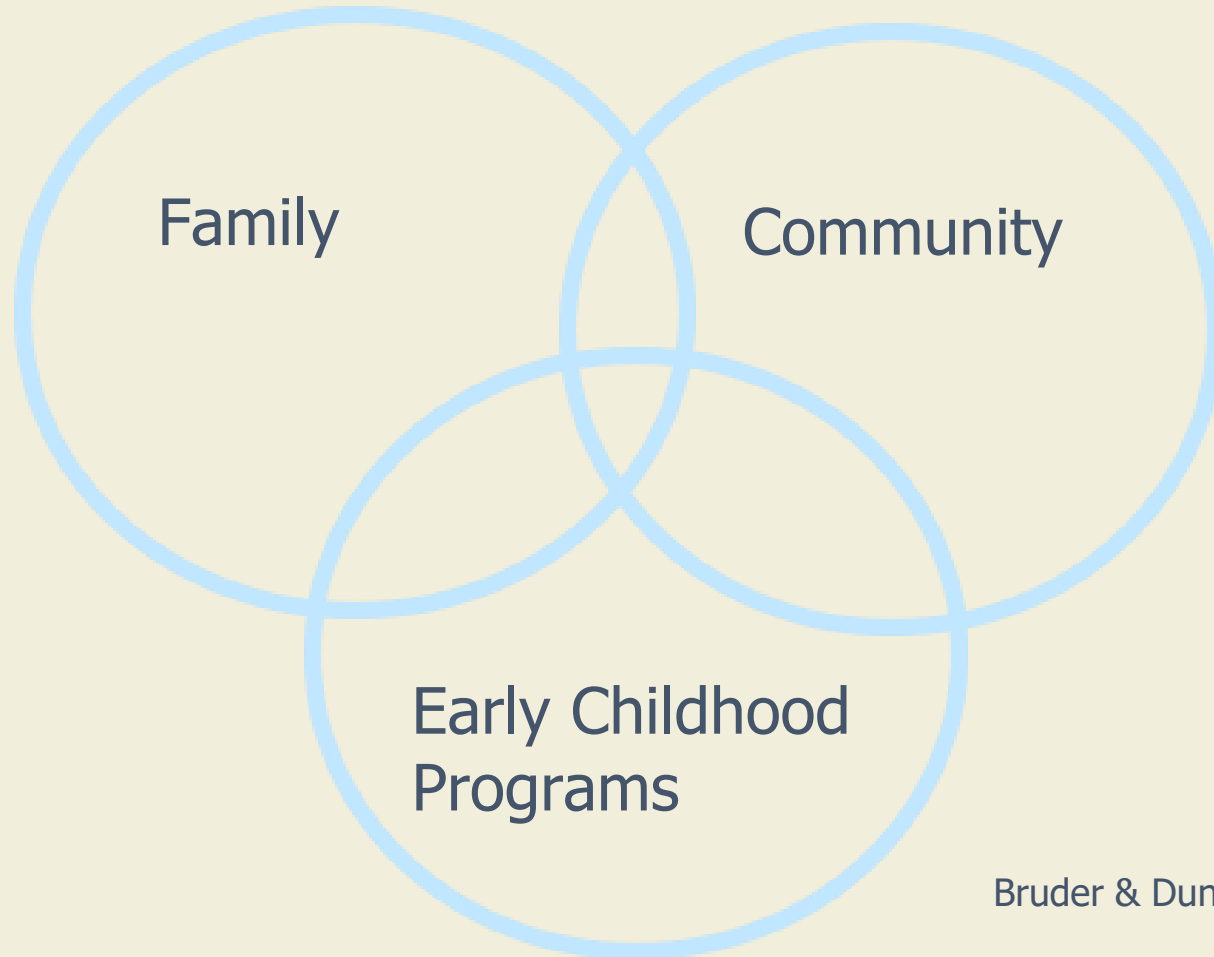
Resources: Routines

- [Learning Module: Routines for Participation and Learning](#)
 - [Rutinas para la participacion y el aprendizaje](#)

- [Incorporating Active Learning Theory Into Activity Routines](#)
 - [En Español](#)

- [Learning Module: Calendars](#)
 - [Calendarios](#)

Sources of Children's Learning Opportunities



Bruder & Dunst, 1999

Trusted Relationships

- Facilitate access, communication, and social interaction
- Bonding & Respect
- Enter child's world
- Provide Consistency

Resources: Building Relationships

- [Harmonious Interactions](#)
 - [Interacciones Armoniosas](#)
- [Conversations: Connecting and Learning with Persons who are Deafblind](#)

Families

- Family-Professional Partnerships are essential for promoting optimal outcomes for children with deaf-blindness.
- Parents should be supported in their role as advocates.
- Siblings often experience unique joys and frustrations in their role and may benefit from sibling support programs.

Effective Family Support

- Having a child with complex needs has an enormous impact on family dynamics.
- Providers need to support families in assessing their needs and creating a plan that supports not only the individual with a disability, but each member of the family towards a trajectory for a good life.

Charting the Life Course (CtLC)

CtLC is a framework for assessing family needs that identifies:

- What's working
- What's not working
- Needed next Steps

It allows a family to tell their story to educational teams and service providers.

Supporting the Needs of the Person and Family

Individual and family supports address all facets of life and adjust as roles and needs of all family members change.



Discovery & Navigation
(Info and Training)

Connecting & Networking
(Talking to someone that has been there)

Goods & Services
(Day to Day, Medical, Financial)



Person and Family Level Quality of Life Domains



Daily Life and Employment
(school/education, employment, volunteering, routines, life skills)



Healthy Living
(medical, behavioral, nutrition, wellness, affordable care)



Community Living
(housing, living options, home adaptations and modifications, community access, transportation)



Safety and Security
(emergencies, well-being, legal rights and issues, guardianship options and alternatives)



Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)



Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)



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DEAF-BLIND NETWORK
TECHNICAL ASSISTANCE ACROSS THE NATION



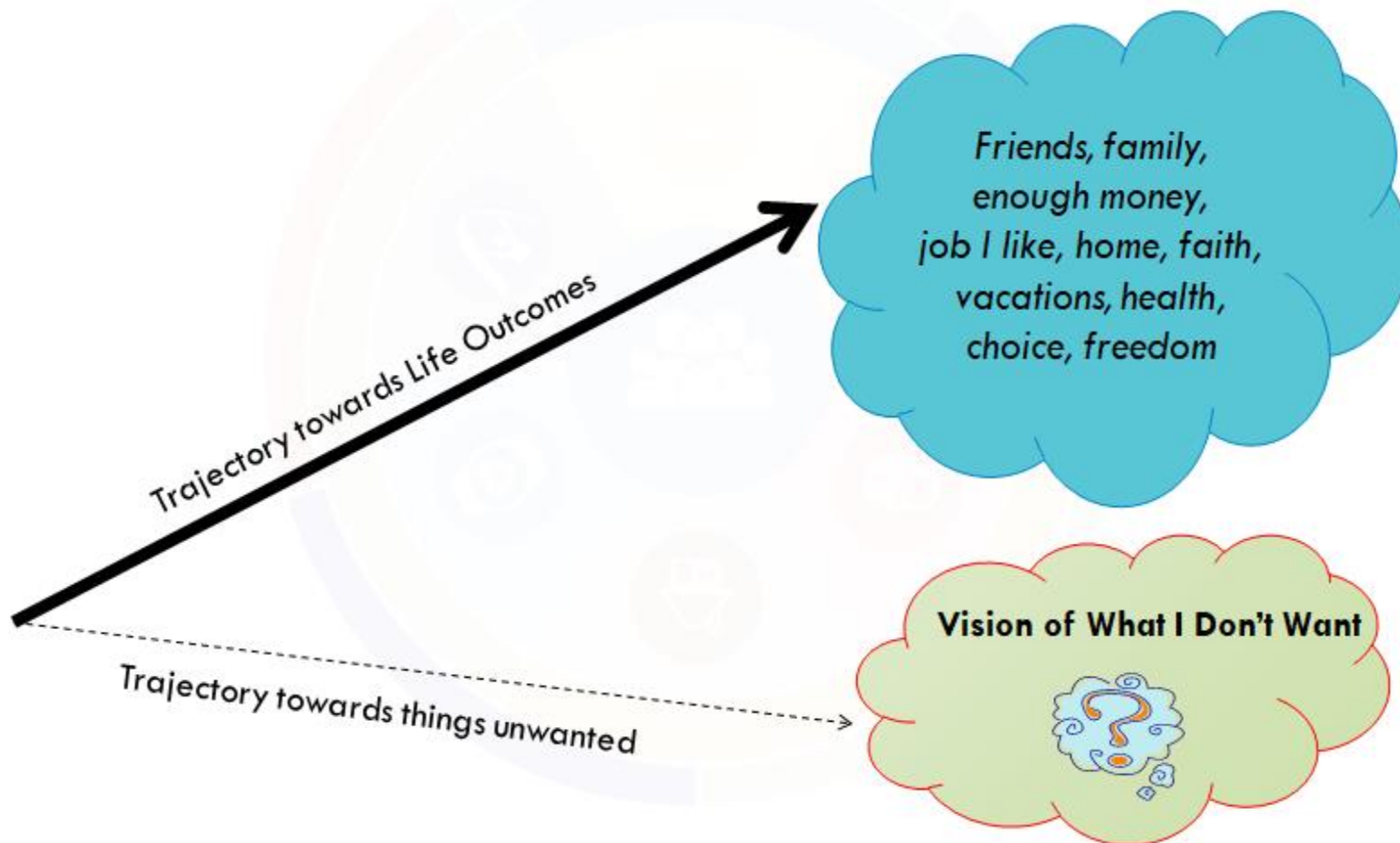
Trajectory of Life Experiences

Individuals and families can reflect on prior and current life stages and experiences while focusing on the future.

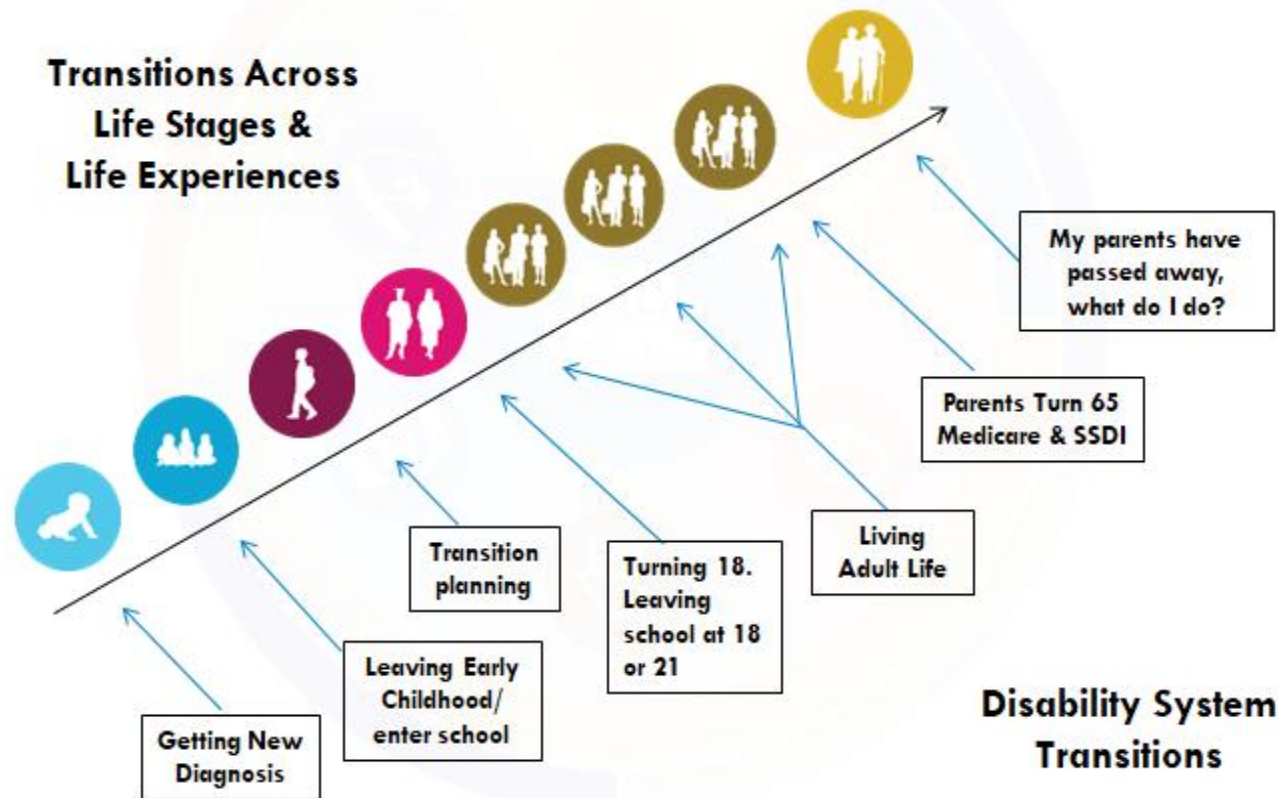
A vision creates opportunities for life experiences along the life trajectory.



Trajectory towards Good Life



Trajectory Across Life Transitions

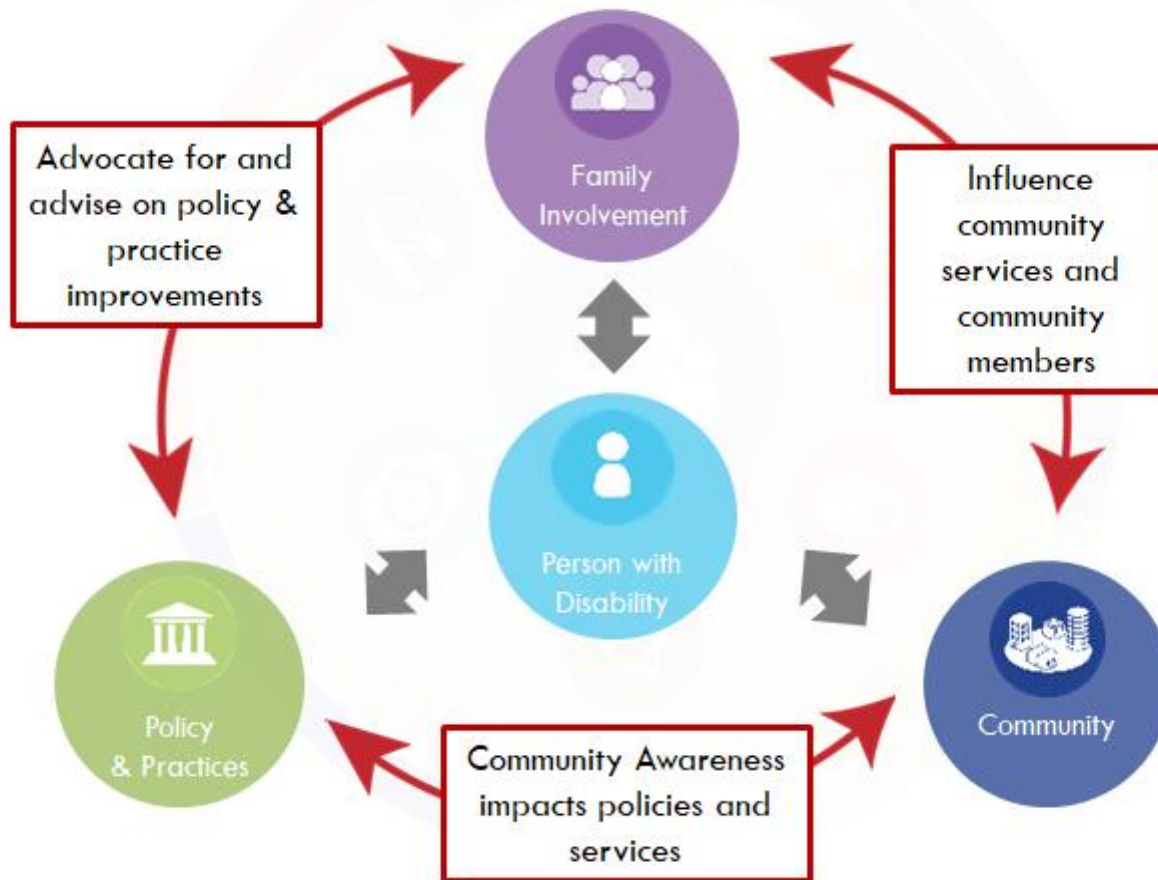


Integrated Service and Supports

Individuals and families utilize an array of integrated services and supports to achieve the envisioned good life



Benefits of Family Engagement



Creating a Shared Vision for Parents and Team Members

Used during Early Childhood Transition Planning Meeting



CHARTING the life course
MAX's ONE-PAGE PROFILE

What people like to know about me

- Funny
- Cute
- Little
- Complimentary
- Affectionate
- Energetic

What's important to me

- Attention
- Family
- Toys
- Food
- Cooking with mom

How to best support me

- Boundaries
- Consistency
- Appropriate affirmation

Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

Technology: - likeable, - social, best - affectionate, no entime

Personal Strengths & Assets: - he was in pre-school/peer relationships (childcare)

Relationship Based: Goal for Academic readiness

res neighbor, kid - good relationship

- Biological Mother bases a lot of decisions on scheduling needs - but feels full time pre/childcare is the answer

SCHOOL SUCCESS

- appropriate behavior and social functioning
- positive relationships
- consistent expectations

WHAT DOES THIS MEAN?

- expression of their best support system to give him different learning modalities
- structured peer partners
- appropriate expectations

<http://www.lifecoursetools.com/lifecourse-portfolios/>

Puerto Rico Neonatal Universal Hearing Screening Program Information, of the Department of Health (Programa de Cernimiento Auditivo Neonatal Universal (PCANU))

- For more information, call PCANU at 787-765-2929, exts: 4592, 4593, o 4577
- Is part of the Division of Children with Special Medical Needs, created in 2004 under the Law 311 of December 19, 2003. It is the Program responsible for making neonatal hearing screening to all the newborns in hospitals in Puerto Rico before they are discharged. In addition, if the infant is born out of a hospital, it is compulsory to make a hearing screening before the first month of age.

Puerto Rico Deaf-Blind Project Information

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References 1 of 2

Chen, D. (Ed.). (2014). *Essential Elements in Early Intervention: Visual Impairment and Multiple Disabilities*. New York, NY: AFB Press.

Chen, D. with Klein, M.D., Holloway, E., Myck-Wayne, J., Saledo, P., Snell, R. (2008). *Early Intervention in Action: Working Across Disciplines to Support Infants with Multiple Disabilities and Their Families*. Brookes Publishing Company. Baltimore, MD.

Dunst, C.J. & Bruder, M.B. (1999). Increasing children's learning opportunities in the context of family and community life. *Children's Learning Opportunities Report*. Vol. 1, No. 1. <http://www.puckett.org>

Dunst, C.J. & Bruder, M.B. (1999) Family and community activity settings, natural learning environments and children's learning opportunities. *Children's Learning Opportunities Report*. Vol. 1, No. 2. <http://www.puckett.org>

References 2 of 2

Gleason, D. (2005). *Sensory Functioning Assessment and Intervention Strategies: Children with Visual Impairment and Multiple Disabilities*; Perkins School for the Blind-Hilton/Perkins Program.

McWilliam, R. A. (2010). *Routines-Based Early Intervention: Supporting Young Children and Their Families*. Baltimore, MD: Paul H. Brooks Publishing Co.

Miles, B. & Riggio, M. (Ed.) (1999). *Remarkable Conversations: Guide to Developing Meaningful Communication with Children and Young Adults Who are Deafblind*. Perkins School for the Blind.

Rush, D.D., Shelden, M.L., & Hanft, B.E. (2003). Coaching families and colleagues: A process for collaboration in natural settings. *Infants and Young Children*, 16(1), 33-47.

Rush, D.D. & Shelden, M.L. (2005). Implementing evidence-based practices in early childhood intervention: Coaching in early childhood. Training materials, Sept. 12-14, 2005, Topeka, KS.