


SUPPORTING YOUNG CHILDREN WITH DOWN SYNDROME IN CHILD CARE AND PRESCHOOL SETTINGS

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WHO WE ARE

Designer Genes is:

- Non-profit 501(c)(3)
- Family based organization
- Represent close to 700 individuals with Down syndrome and their families across the state of North Dakota
- Have been providing supports to individuals and families close to 40 years



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MISSION

To strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong

VISION

We see a community that embraces, respects, and supports people of all abilities, especially those with Down syndrome.

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VALUE STATEMENT

Individuals with Down syndrome are at the center of what we do and we strive for relationships that support our core families.

Designer Genes will embrace people as they are to create supportive and protective communities and viewing the organization as a benefit to the whole.

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EARN, LEARN, AND BELONG



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WHAT WE DO...

- Support for new diagnosis across the state
- Collaboration with Project Carson
- Resources, information, and referrals
- Parent-to-parent support
- Education supports
- Family activities
- Trainings
- Public awareness
- Health care access supports
- Library materials/resources
- Advocacy



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BIG EVENTS

- Annual Designer Genes Events
 - Family Bowling
 - Family Picnic
 - Supper with Santa
- iCan Bike Camp
- Annual Walk for Down Syndrome
 - Save the date: Sept 27th



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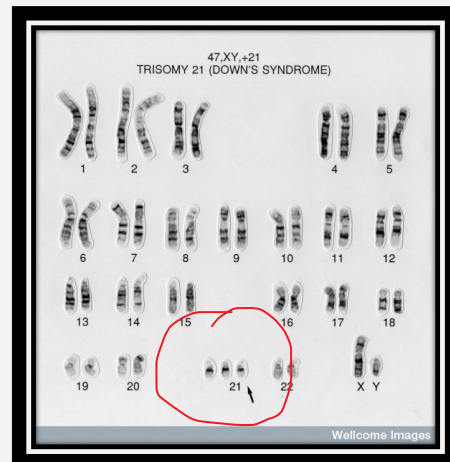


DOWN SYNDROME FACTS

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WHY DO PEOPLE HAVE DOWN SYNDROME

- How are we the same?
- How are we different?
- What makes us different?
 - Cells and Chromosomes



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A FEW FACTS...

- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, sleep difficulties, vision and hearing impairments, Alzheimer's disease, childhood leukemia, pulmonary problems, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

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AND A FEW MORE

- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to lead fulfilling and productive lives.
- Every person with Down syndrome is an individual first! A wide range of variation in the developmental needs impact learning.



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Just Like You-Down Syndrome



<https://youtu.be/5M--xOyGUX4>

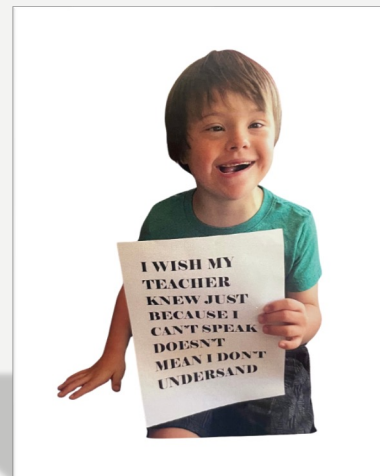
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SUPPORTING PERSONS WITH DOWN SYNDROME

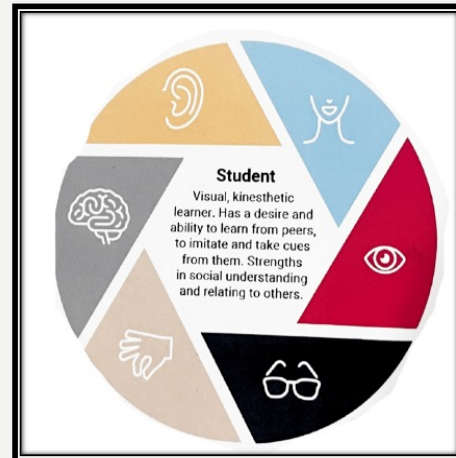
- Remember Down syndrome and Forget Down syndrome
 - Provide accommodations
 - Visual cues and pictures
 - Extra Time
 - Clear, but not louder communication
 - Have typical expectations
 - Same rules
 - Expect Learning and a desire to learn
 - Speak to the person, not the support staff
 - Never underestimate the power of a relationship and natural learning



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SUPPORTING CHILDREN WITH DOWN SYNDROME AND BEHAVIOR

- Predictable schedules
- Pre-teaching on changes
- Pre-teaching through use of social stories
- Clear, simple, instructions with visual cues
- Teach and use visuals
- Age-appropriate expectations
- Consistent responses
- Increase engagement and interaction
- Foster friendships and play ideas
- Find ways to build independence and choice
- Clear and factual communication with parents



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PEOPLE FIRST LANGUAGE – WWW.DISABILITYISNATURAL.COM

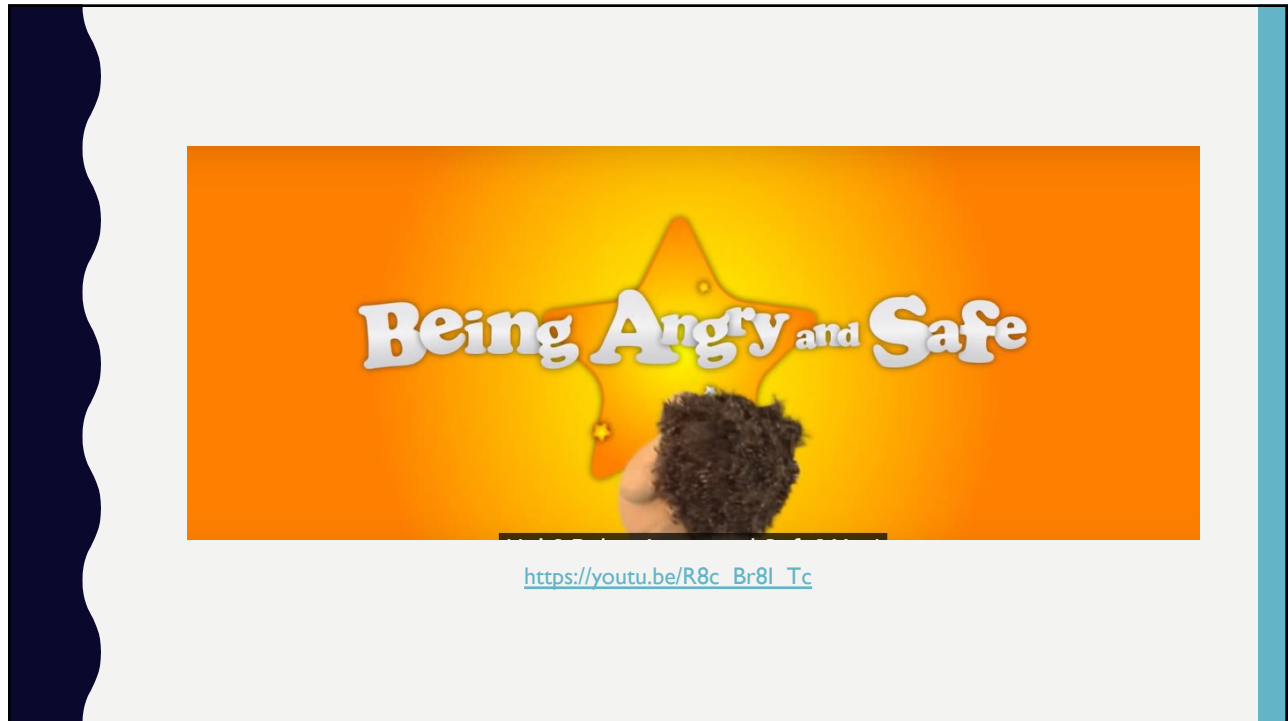
- Person with Down syndrome
 - Not Downs
 - Not “Downs child”
- Intellectual or Cognitive Disability
 - Not Mental Retardation
 - Help us to correct use of “r” word
- Speak to the person, listen to their language

"How you *choose* to
address me impacts
me more than my
disability."

Cindy Lumpkin

www.theldcoach.com

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UNDERSTANDING SYSTEMS OF SUPPORT... ND EARLY INTERVENTION

- Children with Down syndrome (ages Birth to 3) are automatically eligible for the ND Early Intervention system, which is statewide.
- Most children are referred before or at birth and would not need Right Track
- The state is divided up into 8 regions. Single point of entry are the regional Developmental Disability Units.
- Professional services are delivered by providers within the region.
- What children and their families get:
 - Service Coordination
 - Individual Family Service Plan development (IFSP)
 - Access to Medicaid
 - Developmental Assessments/Evaluations
 - Professional services delivered in Natural Environments
 - Support with Transition to other services and supports after 3

Individualized Family Service Plan

- The Individualized Family Service Plan (IFSP) is both a process and a legal document intended to assist families and professionals in a community in their combined efforts to meet the developmental needs of a young child with special needs from birth to age three.
- Outcomes are established
- Family-Centered
- Allows for change
- A written plan to help determine who will do what to help the child reach their goals

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UNDERSTANDING SYSTEMS OF SUPPORT...EARLY CHILDHOOD SPECIAL EDUCATION

- Most children (ages 3 – K) with Down syndrome transition from Early Intervention services to supports through their local school districts
- Children must be eligible for Early Childhood Special Education (ECSE) services through delays in their skills, not diagnosis.
- Children will receive services based on the decisions of their Individual Education Plan (IEP) team.
- An IEP is child-focused and will not address family goals like an IFSP in Early Intervention.
- ECSE and/or a Special Needs Preschool is special education as we know it in the public school and the same rules and regulations apply.
- Often children with Down syndrome will also continue services through Developmental Disabilities Program Management at the Human Service Centers, but this is not automatic and not connected to special education eligibility.

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WHAT CAN YOU DO?

- Explain to the parent that you are interested in helping them achieve any goals/outcomes that the child has
- Ask to have the parent review the IFSP/IEP with you.
- Continue your typical routine when a provider visits you
- Be involved in any planning meeting if it's possible or ask if it can be videotaped.
- Use video as much as possible (with parents' permission) to demonstrate skills, behaviors, strategies, etc.
- Share with parent when a provider has been to your home. Parents should always be aware that service delivery happened.



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WHAT CAN YOU DO?



- Explore your resources:
 - Uspire ND – Inclusive Child Care Program
 - Child Care Health Care Plans
 - Local, state, and national diagnosis specific organizations
 - Designer Genes
 - National Down Syndrome Congress
 - Global Down Syndrome Foundation
 - National Down Syndrome Society
 - Division for Early Childhood
 - Family Support Organizations



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USPIRE CONTINUED

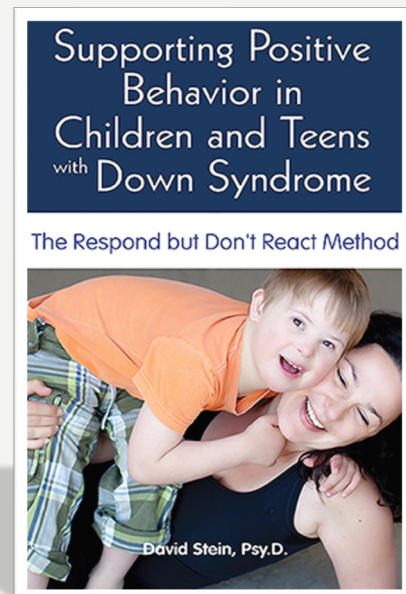
- Inclusion supports connect private childcare programs and families with both coaching and financial resources designed to help assure that children with special needs can maintain their place in an integrated child care setting.
 - 5 inclusion coaches that support more than 1,100 child care programs in ND



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RESOURCES...

- North Dakota Inclusive Child Care Program:
 - <http://www.nd.gov/dhs/services/childcare/inclusion.html>
 - <http://ndchildcare.org/projects/>
- Woodbine Publishing
- National Down Syndrome Society
 - www.ndss.org
- National Down Syndrome Congress
 - www.ndsccenter.org
- Division of Early Childhood
 - www.dec-sped.org
- Family Voices of North Dakota
 - www.fvnd.org
- Project Carson
 - <http://fvnd.org/site/index.php/nd-parent-to-parent/project-carson/>



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THANK YOU!



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