The Up-Side of Down Syndrome: A Workshop for New Parents and Parents-To-Be
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Speaker Disclosure

We are not promoting or selling any commercial-related items in this presentation.

Session Objectives

Participants will gain knowledge from research on the benefits of parenting a child with DS

Participants will be able to identify information and resources that will assist them in their journey as parents

Participants will develop advocacy skills that will assist them in parenting a child with DS
**Down Syndrome: The Facts**

- Down syndrome occurs when an individual has **three**, rather than **two**, copies of the 21st chromosome.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies is born with Down Syndrome.
- The incidents of births of children with Down syndrome increases with the age of the mother.
- Life expectancy for individuals with Down syndrome is 60 years (continues to go up).
- Increased medical risks include heart defects, respiratory and hearing problems. Most lead healthy lives!
- Common physical traits include low muscle tone, small stature, an upward slant of the eyes and a single deep crease across the center of the palm.


**Trisomy 21…so much more than a number : Nicole's Story**

- The pros and cons of having a pre-natal diagnosis
- **Nicole’s Story: The Miracle of Katarina**

**What?!? My baby has Down syndrome! : Briana's Story**

- The pros and cons of a neo-natal diagnosis
- **Briana’s Story: Dalton and His Gang**
Down Syndrome Survey Information

- This was an online survey with quantitative and qualitative questions.
- The survey was distributed nationwide with the help of Down syndrome guilds across the country.
- The NDSC has also published a release on the research in addition to the survey link.
- Over 600 participants have responded and completed the survey.

Why research is important...

- Provides concrete evidence of issues faced by parents of children with DS
- Addresses current gaps in the field (e.g., experiences of fathers, couples)
- Provides direction for education and intervention

What we know...

- Parents of children with DS and other disabilities encounter a variety of challenges associated with raising their children (e.g., developmental, medical, educational) and with more frequency that most parents of typically developing children do not experience.
  - Coping with their child’s condition
  - Understanding what developmental limitations exist
  - Identifying and accessing necessary specialized care and medical services (e.g., occupational therapy, physical therapy, speech therapy)
  - Locating community resources and support, and planning for the future
Almost every study prior to the 1980s anticipated poor outcomes for families of children with DS

Having a child with DS is more like other stressors that families face

Although there may be greater demands on family resources and higher stress levels when there is a member with a disability, stress levels can be lessened by perceived social support and enhanced family coping strategies

There are more similarities than differences between families with and without a child with Down syndrome

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**Our DS Research**

**Sample Research Questions**

- **Quantitative measures on coping (at time of diagnosis) and current relationship satisfaction, life satisfaction, and hope.**
- **Qualitative questions including:**
  - Describe the experience when you first learned of your child’s diagnosis with Down syndrome:
    - What were your initial reactions/emotions/thoughts?
    - What was the process in adjusting to your child’s diagnosis?
    - What was your experience with prenatal testing?
    - Would you make the same decision again?
  - Describe your most positive experience in your journey with your child.
  - Describe your most negative or most difficult experience in your journey with your child.
  - What advice would you have for other families who are preparing for a child with Down syndrome?

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**Study 1: Prenatal and Postnatal Diagnosis Groups**

**Prenatal Diagnosis Group:** 46 participants (3 males, 43 females)
- Average age: 40.2 years; Age range: 26-53
- 87% European American/White
- 84.8% were currently married
- 55.6% reported an annual income > $80,000
- Average age of child with DS: 4.8 years; Child age range: 0-18 years
- 24 (52%) had a male child with DS, 22 (48%) had a female child with DS

**Postnatal Diagnosis Group:** 115 participants (12 males, 103 females)
- Average age: 41.4 years; Age range: 21-69
- 87.8% European American/White
- 87.4% were currently married
- 63.9% reported an annual income > $80,000
- Average age of child with DS: 7.6; Child age range: 2 months- 45 years
- 65 (57%) had a male child with DS, 51 (44%) had a female child with DS
Prenatal Screening/Testing Decision by Parents

Prenatal Group:
- 31 (67%) would make the same decision again

Prenatal Parent
- “Looking back, I am glad that we did prenatal testing just so that we could be prepared and knowledgeable before our son was born. It made delivery day a happy day – and not one that was tainted with a diagnosis” (Prenatal #15).

Postnatal Group:
- 40 (35%) would make the same decision again (to not have prenatal screening/testing)
- 45 (39%) reported that they had a negative prenatal screening result (so they did not pursue further testing)
- 15 (13%) indicated they would have prenatal screening/testing in the future

Postnatal Parent
- “I liked the idea that there wasn’t a black cloud hanging over me during my pregnancy” (Postnatal #19).

- “[My son] and his gentle disability have gently walked us through acceptance, one phase after another, and we have been grateful for that considerate acceptance process. Given the choice now we would choose testing to get the proper professionals on hand to support the birth and prepare for early intervention” (Postnatal #86).
Parents’ Adjustment

- Parents in both groups indicated that their initial reactions to learning that their child had Down syndrome were those of grief, fear, mourning, overwhelmed, denial, guilt, anger… almost every human emotion.
- “It was like having every possible emotion all at once…the full range of emotions.”
- Grief and devastation generally came from feelings of loss in relation to the image that parents had of their future child and the vision of the future of their family.
- “We cried until there were no more tears. All we could think was that it was somehow our fault and that his future would be so difficult. That our perfect baby we dreamed of was now far from that image we had.” (Postnatal #26)

Parents’ Adjustment—Process of Adjustment

- Parents in both groups varied in how long the process was in adjusting to the news, from almost immediately to several months.
- More postnatal (26%; n = 30) group participants compared to prenatal group participants (15%; n = 7) indicated that they had a shorter adjustment time.
- A primary factor that contributed to the adjustment process involved the adjustment to the DS diagnosis when other medical problems were the primary focus.
- Participants in both the prenatal (26%; n = 12) and postnatal (23%; n = 26) groups reported that their child also had other medical issues.
- “The diagnosis of partial AV canal put our daughter’s DS diagnosis into better perspective immediately for us. She might walk, talk and read later than most kids, but our primary concern would be to keep her healthy and enjoy the gift of her life.” (Prenatal #25)

Resources and Support for Parents: Experiences with Medical Professionals

- Participants reported both negative and positive experiences with medical professionals.
- Negative experiences outnumber positive experiences 2.5:1
- Prenatal Group: 35% (n=16) indicated negative experiences
  - Medical professionals’ insistence on terminating the pregnancy (n=11)
  - Perpetuation of negative stereotypes of individuals with Down syndrome (n=7)
  - Lack of information about Down syndrome provided by medical professionals (n=5)
  - Lack of compassion exhibited by medical professionals (n=4)
- Postnatal Group: 24% (n=27) indicated negative experiences
  - Lack of compassion when explaining the diagnosis (n=17)
  - Pressure to have prenatal testing (n=4)
Positive Medical Experiences

- 11% (n=5) prenatal group participants indicated positive experiences with medical professionals
- 4% (n=5) postnatal group participants indicated positive experiences with medical professionals
  - professionals discussed other options besides termination of the pregnancy
  - medical professionals provided resources immediately after the diagnosis

Prenatal Parent

“Staff at the hospital were very negative concerning Down syndrome, not one piece of help or positive outlook from anyone, we were given leaflets on abortions and burials but nothing about the positive side of having a child with DS. We were given no counseling, nothing... Staff at our local hospital, when they found out about our baby’s heart were negative and I felt I was having a monster not a baby.”

Postnatal Parent

“We took our son to a pediatrician in our neighborhood who referred to him as ‘children with problems’. I never saw my son having Down syndrome as a problem. I really feel that all children (and people) have needs and anything my son was needing was part of his needs, not a problem.”

Resources and Support for Parents: Seeking Information, Education and Support

- Participants in both groups reported actively seeking information about DS as a resource.
- Seeking information and support included:
  - Seeking information on the internet
  - Meeting with medical specialists or securing services for their child
  - Connecting with other parents of children with DS or DS organizations
  - Seeking support from family/friends
Prenatal Parent

“...I then spoke with all contactable friends and relatives and was shocked at how negative they all were in their reactions. This made me think that maybe I could cope with this, as I realized I didn’t see it as the death sentence or extreme tragedy that they all did. I did a lot of research immediately...I realized I didn’t know enough about the condition and that all my preconceptions were wrong.”

Postnatal Parent

“The more I learned, the less afraid I was. Our local Down syndrome group was a great help to me, as were several online message boards... I got to see what real families were dealing with, and I started to feel much better.”

Negative Experiences

A few participants in both groups reported negative experiences when seeking information or outside support.

- researching information was “overwhelming,” “frightening,” or “depressing”
- outdated information
- negative reactions or lack of support from family and friends
- support groups were focused on “mourning” rather than celebrating their children

Resources and Support for Parents: Faith/Religion as a Resource

- 17% (n=8) of prenatal group participants described how faith/religion played a role in their adjustment to their child’s diagnosis
- 20% (n=23) of postnatal group participants described how faith/religion played a role in their adjustment to their child’s diagnosis
Study 2: Prenatal and Postnatal Groups
Quantitative Data

- The main focus of this study included parents’:
  - Coping (at dx)
  - Life satisfaction
  - Family satisfaction
  - Hope

- Compared participants with prenatal screening/testing (n = 105) and from a postnatal diagnosis (n = 294)

- The results indicated no statistically significant differences between the two groups on the measures of coping, life satisfaction, hope or relationship satisfaction.

Prenatal-Postnatal Conclusions

- "We’re more alike than different!"

- "Flashbulb memory”
  - Parent descriptions of learning about their child’s diagnosis was as clear as if it had just happened, regardless of when the diagnosis occurred
  - Description of the moment of diagnosis involved overwhelming emotions, including grief, loss, mourning, guilt, and anger

Prenatal-Postnatal Conclusions

- Assisting families with navigating this new path involves:
  - Providing new parents with accurate information regarding their child’s diagnosis
  - Connecting them with effective resources and sources of support
  - Encouraging the development of a positive perspective, emphasizing the resilience and positive experiences of families of children with DS and other special needs
Benefits to Parents: What We Know About This Journey

“Where this little life was no accident! She was exactly how the Lord intended her to be.”

“So when I was holding my baby and received his diagnosis, it was the first time in my life that I knew without reservation that there is a God. I felt like He gave this child to me as a gift and prepared me ahead of time to recognize it as exactly that - a precious gift.”

“Without being able to explain it, I knew I was in for something special.”

“God gave us this gift. A gift to help our family become more loving and caring to each other and those around us. Our little boy with DS is the best gift I could have ever gotten.”

“I do not consider myself religious, but I know that God has brought me this child to teach me something more important about life.”

Advice to Parents by Parents: Seek Resources and Information

Themes:
- Network/Interact With Others
  - “Meeting with families who have an older child with DS will ease a lot of fears and are a great source of support.”
- Obtain ‘Accurate’ Info
- Acquire Medical Team
- Parent Role is... Advocate
  - “Don’t be afraid to speak up, not even to a doctor.”

Expect, Don’t Accept Less

Themes:
- Treat Your Child Like any Other
  - “Treat them like any other kid, do not handle them as if they are a porcelain doll.”
- You Will Love Your Child
- The Child is Life Changing
  - “They will grow and learn so many new things because of their child.”
- Take One Day at a Time
Your Child is...

Themes:
- A Baby/Child First
- A Precious Gift/Blessing
- Unconditional Love
- Happiness/A Joy

It’s an Emotional Process

Themes:
- Preparation - “The more that you can do earlier like therapy, braces, surgeries, etc the better and faster progress can be.”
- Support - “Surround yourself with people who are proud of you, who support you.”
- Grief - “Grieve the loss of child that you thought you were having.”
- Self-help - “Get whatever help YOU need.”
- Be emotional - “It’s okay to be sad and angry.”
- Fear or Shock - “Know that the fear, and grief and dominance of the ‘Down syndrome’ diagnosis, will recede in time.”

Find Encouragement

Themes:
- Look on the Bright Side
  - “Know that your life is not over and you are not doomed to live on ‘sad street’.”
  - “When it gets tough, watch them sleep.”
- It’s Not Your Fault
  - “There is nothing you did for this to happen. It happens the instant the egg is fertilized and splits. You cannot control it.”
- Find Success Stories
  - “She told me of her son graduating and having 2 dates for the prom. Even I didn’t go to my prom and here her son with DS had 2 dates!! That gave me hope.”
Summary:

- Grief and loss: It's ok to grieve (and normal!)
- Process of adjustment may take time (months or years)
- Joy and hope: finding the positives along the journey
- Get (and stay!) connected
- Kids are Kids (no matter how many chromosomes they have!)

Developing Your Advocacy Skills: Special Services

- Parents’ experiences with common problems in infants and toddlers
- Specialty Clinics and Services
  - Understanding the maze of professional providers who have just entered your life: Who does what and how to get them to do what they are supposed to do
  - What you should know before your first appointment
  - Following up and becoming your child's advocate in the health-related “systems”

Advocating for your child...

- What does “advocating” mean?
  - Some examples...
- As a parent, you are the best and sometimes only voice for your child!

- Listen to and follow your instincts—You know more than the doctors (although they won’t admit it!)
The initial impact of receiving a Down syndrome diagnosis is often characterized by shock, fear, and grief. However, the intense emotional responses are considered normal given the circumstances of adjusting to a different life than was originally dreamed of for one’s child. Parenting a child with Down syndrome seems to require a process of readjusting expectations, seeking out resources, and identifying a new dream; but doesn’t mean surrendering any and all expectations for the child or the family. This parenting journey is filled with challenges, like any other parenting experience, but is often described as life changing in a very positive and meaningful way. Children with Down syndrome are often described as ‘joy, happiness, unconditional love, a gift or a blessing.’ The biggest challenge associated with this parenting journey is related to interactions with medical professionals and systems of care. There continues to be a narrow range of information provided to parents upon diagnosis, inaccurate or largely discouraging descriptions of DS, a lack of sensitivity by the ones delivering the news, and a lack of systematic support offered to families. Ultimately, there are no guarantees with any child, and parenting one born with DS is truly more similar than different than raising a ‘typical’ child, and at times even better than one could imagine.

Web resources:
- http://www.ndsccenter.org/
- http://www.autismspeaks.org/
- http://www.ada.gov/
- http://www.who.int/topics/disabilities/en/
- http://www.iser.com/
- http://www.education.com/topic/special-needs/
- http://bridgingapps.org/ - Apps for disabilities

The End...