Making Connections
That Count

Strategies to help you build a strong support network for people with Down syndrome

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Goals for this keynote

Build a tribe
Sound the rally call
Balancing act
Building Your Tribe

- Don’t build a moat around your family
- Teach by example
- Share challenges and ask for help
- Provide support strategies
- Check ego at the door
- Don’t expect special treatment
- Have clear expectations
- Give second chances
- Don’t sugarcoat, but don’t overshare
A new way of looking at Down syndrome

- Natural part of the fabric of society
- Embrace differences/uniqueness
- More alike than different
- Not one size fits all
- Encourage people with Down syndrome to drive the bus
Family Connections

- Talk openly about Down syndrome
- Don’t make everything about Down syndrome
- Focus on today and don’t borrow trouble
- Make and share your long range vision
- Educate family members
- Encourage family to get involved with local Down syndrome organization
Educators and Therapists

- Embrace them as if they are a part of the family
- Remember their reason for going into this field was to help children
- Provide resources and support
- Encourage them to reach out to colleagues
- Nominate for awards and recognition
Educators and Therapists

- Provide All About Me Booklet
- Bring treats to IEP meetings
- Don’t make extra work for them
- Celebrate successes together
- Mars and Venus
- 360 degree approach to behaviors
Educators and Therapists

- You want the professional who wants your child
- Be open to trying new things, but build in an exit strategy
- Be well read on current best practices
- Join the PTA, Special Needs Advisory Board
- Write goals that make sense
Faith Life

- Ask other parents
- Determine what your family’s spiritual needs are and meet with the pastor/priest/bishop to discuss
- Explore churches with special needs ministries
- Try respite nights and mom’s day out programs as well as worship services
- Modify your worship practices
Medical Professionals

- Have myopic view of Down syndrome
- Listen to parental concerns
- Follow DS healthcare guidelines
- Help coordinate specialty services
- Engage with local Down syndrome clinic
- Get a second opinion
- Have good rapport with patient
What if the Unthinkable Happens?

- Too late to plan when person goes missing
- Create emergency response plan BEFORE a tragedy happens
- Include neighbors and community members in search plan
- Start with most dangerous scenario and work backwards from there
- Know the triggers and likely places
What if the Unthinkable Happens?

- Identification on person with Down syndrome
- Anyone can get involved and return to safety with clear directions
- Teach person with Down syndrome to swim
- Visit police station, fire station and notify them of your situation
- GPS, alarms, locks, emergency response plan
Neighbors and Community Members

- Invite to walks, school plays, dance recitals, birthday parties.
- Support other kids
- Included in your emergency response plan
- Too many prompts/transitions
You’re UNDER thinking it

- Sexuality education is critical
- 39 years outside of high school
- Teach independence and not learned helplessness
- Be aware of services, how to apply and when
- 80% of people with Down syndrome are unemployed or under employed
You’re OVER thinking it

- Presume competence
- Promote independence
- Life is full of non-preferred activities
- Don’t anticipate needs and meet them
- Allow for processing time
- Person with Down syndrome has their own agenda
Successful Adults With Down Syndrome

- Have good coping strategies
- Know how to ask for help
- Make mistakes and learn from them
- Have disabled friends and typical friends
- Lead authentic adult lives
Successful Adults

- Meaningful daytime activities
- Give back to their families and communities
- Have good social behavior
- Use technology
- Have meaningful relationships
KEEP CALM!

[Image of a child wearing a t-shirt that says, "KEEP CALM IT'S ONLY AN EXTRA CHROMOSOME"]
A Strong Support Network

- Embraces your long range vision
- Sets the bar high
- Recognizes potential
- Challenges person with Down syndrome
- Provides feedback and embraces natural consequences
- Doesn’t over praise, over reward or over prompt
- Follows the lead of person with Down syndrome
Adult Life

- Channel his/her passion
- Contextual learning
- Manipulative or hands on activities
- Visual cues
- Processing time
- Positive note home to parents about the day’s events
How do I motivate student without rewards?

- As soon as we do X then we do Y
- Partner student with peers to do task
- Intermittent praise
- Show confidence in your student’s abilities
- Offer help as needed
Believing in Achieving

- Exposure, exposure, exposure
- Teach person the way he/she learns
- Follow person’s lead
- Watch out for those Mother Hens!
- Lifelong learners (NO ONE PLATEAUS)
What does the future hold?

- Living until 55-60?
- Living away from home?
- College? Employment?
- Marriage?
- Will parents be exhausted caregivers?
Hard work pays off
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