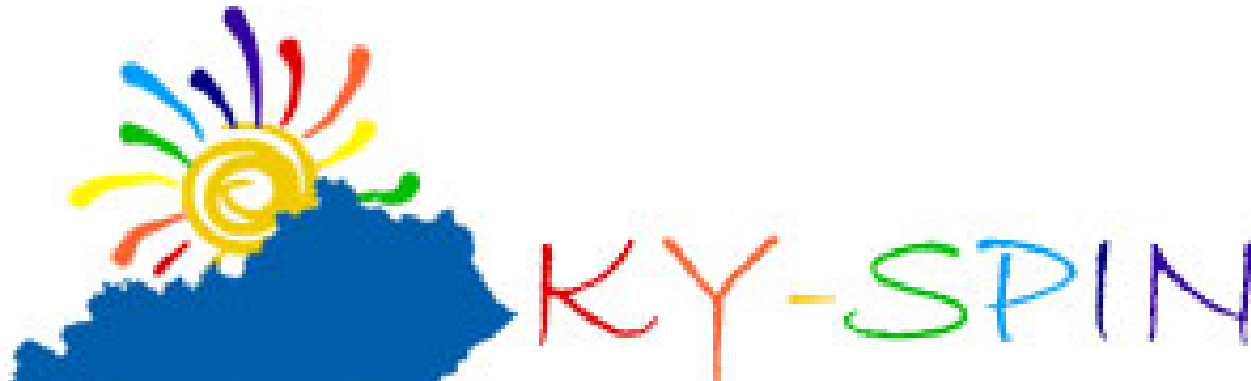


KY-SPIN PRESENTS  
LUNCH AND LEARN

# Empowering Conversations

How to Talk to Your Child About Their Disability

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# Kentucky Special Parent Involvement Network (KY-SPIN)

## Parent Training & Information (PTI) Center

Funded by the U.S. Dept. of Education under IDEA since 1988 when Kentucky first received a PTI. KY-SPIN Parent Center provides training, information and support for children and youth with all types of disabilities (birth through 26 years old), their parents, families and professionals.





We do NOT

Act as attorneys

We DO

Empower families to advocate for their children effectively.

Provide “peer to peer” support to help families access needed information and resources

# Disclosure

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This is not a Training of Trainers event. KY-SPIN does not authorize other agencies, organizations or individuals to train material.

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# Agenda

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- Understanding Emotions
- Why
- When
- Research
- Conversation

# No “Correct” Answers

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We aim to empower you with the confidence and knowledge to ensure this conversation is positive, impactful and fosters an environment of openness and trust in your family.

However, you decide to talk to your child about their disability is up to you.

There are no manuals for parenting

This presentation is a guide for how you can talk to your child

You decide how, why, and when you speak to your child about their disability.



# Understanding Emotions

Parental Stress

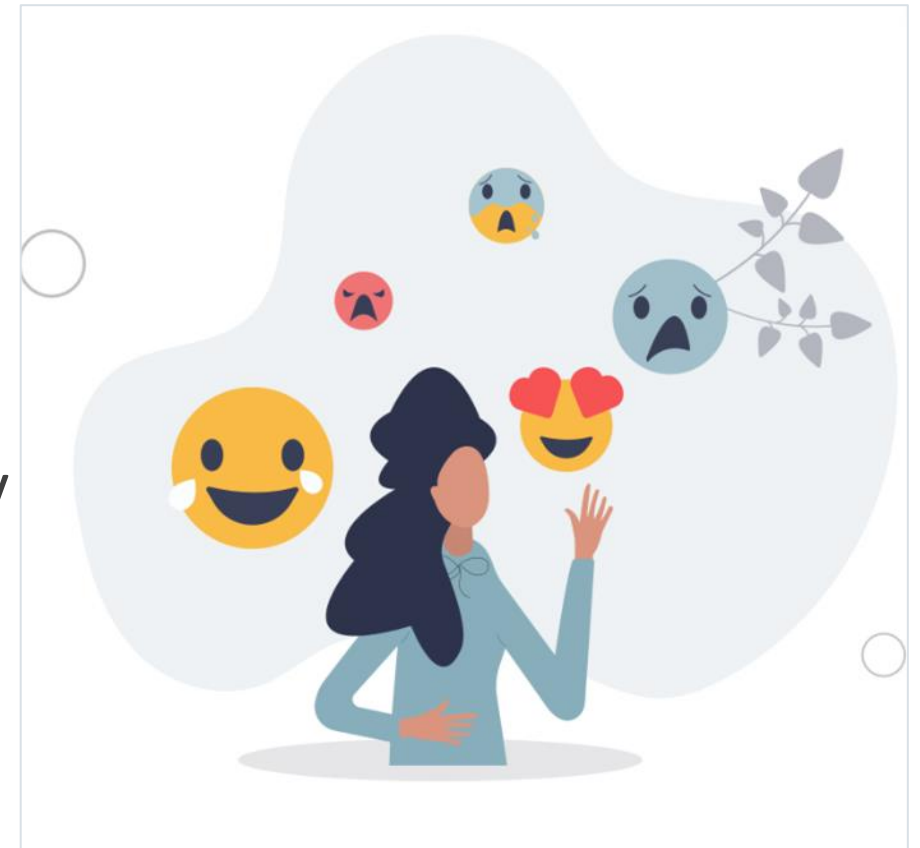
Understanding your reaction

Examples of emotions parents feel after a diagnosis

- Fear, guilt, isolation, grief, depression, anxiety

Adjustment period

It takes time to learn positive coping strategies



# Understanding Emotions

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When your child is diagnosed, it may make a difference in how you adjust

Before birth

After birth





# Understanding Emotions

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Like a stone thrown into a pond, a diagnosis ripples and affects more than one person.

A diagnosis can affect other people in your life

- Grandparents
- Siblings
- Neighbors
- Friends



# Understanding Emotions

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## Reach Out for Help

Support groups

Peer-to-peer support is beneficial

- Parents
- Families
- Siblings

Everyone will deal with a diagnosis differently.



# Why have the conversation?

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To help the child/children become a self-advocate

To give them a chance to develop a positive self-image that includes their disability

- If this is a lifelong disability, coming to terms with it earlier will help them discover how they feel about it

Give accurate information

- Younger children can make up reasons for their disability
- Older kids may get inaccurate information from the internet or peers



# When to have the conversation?

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No “right” age

Young adults with disabilities who weren’t told/sheltered from their diagnosis

- Wish they’d known sooner
- Use the language of the disability to let them know what is going on

They may not understand right away

- Keep it age-appropriate
- Ongoing conversation

# Research

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Kids have questions

- The better you understand their disability, the easier it will be for them to understand

Give your child time to digest what is being said and time to ask questions

Talk with members of the disability community

- Many people with disabilities are there to help others in their self-exploration journey
- Find a support group



# Conversation

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Be factual

Use medically accurate words

- Using “flowery” words can be confusing

Use language at their level

- Preschool
- Elementary
- Middle school/High School



# Conversation

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Encourage questions

Keep an ongoing conversation

Make the discussion with the whole family

Ensure everyone is on the same page

Show in a positive light how each family member is different

# Conversation

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Stay positive

Stay away from words that could let your child interpret them as negative

Avoid derogatory terms

This can be difficult and requires you to keep up-to-date

Words like high functioning and low functioning can be offensive

Using words like severe sounds judgmental, try significant





# Overcoming Obstacles

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Frame their disability around what they CAN do

Acknowledge difficulties

- Validate their feelings
- Don't ignore their disability.

Validate the hardship but help by working on solutions together.

Websites, support groups, and finding others with similar disabilities and see how they overcome hardships



# Remind them

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- Their strengths
- Disability does not define your capabilities in life
- They are a person first, you are not your disability
- You can accomplish your dreams
- Your Voice Matters
- This is your life, with self-determination you can accomplish great things







# References

- Ainbinder, J. G., Blanchard, L. W., Singer, G. H., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology, 23*(2), 99–109. <https://doi.org/10.1093/jpepsy/23.2.99>
- Ayers, K. (2022, January 25). *How to talk to kids about people with disabilities*. Cincinnati Children's Blog. <https://blog.cincinnatichildrens.org/healthy-living/child-development-and-behavior/how-talk-kids-people-disabilities/>
- Cheng, A. W. Y., & Lai, C. Y. Y. (2023, July 24). *Parental stress in families of children with special educational needs: A systematic review*. National Library of Medicine. <https://www.frontiersin.org/articles/10.3389/fpsy.2023.1198302/full>
- Gadsen, V. L., Ford, M., & Briener, H. (Eds.). (2016). *Parenting Matters - NCBI Bookshelf*. The National Academies of Sciences, Engineering, Medicine. <https://www.ncbi.nlm.nih.gov/books/NBK402024/>
- Spratt, E. G., Saylor, C. F., & Macias, M. M. (2007, March 10). *Assessing parenting stress in multiple samples of children with special ...* Families Systems & Health. [https://www.researchgate.net/profile/Eve-Spratt/publication/232516749\\_Assessing\\_Parenting\\_Stress\\_in\\_Multiple\\_Samples\\_of\\_Children\\_With\\_Special\\_Needs\\_CSN/links/58c2c23345851538eb805e64/Assessing-Parenting-Stress-in-Multiple-Samples-of-Children-With-Special-Needs-CSN.pdf](https://www.researchgate.net/profile/Eve-Spratt/publication/232516749_Assessing_Parenting_Stress_in_Multiple_Samples_of_Children_With_Special_Needs_CSN/links/58c2c23345851538eb805e64/Assessing-Parenting-Stress-in-Multiple-Samples-of-Children-With-Special-Needs-CSN.pdf)
- Wheeler, M. (2020, May). *Getting started: Introducing your child to his or her diagnosis of autism*. Indiana Resource Center for Autism. <https://www.iidc.indiana.edu/irca/learn-about-autism/getting-started-introducing-your-child-to-his-or-her-diagnosis-of-autism.html>
- Woods, S. (2019). *Ten tips for talking to your child about their autism diagnosis*. UW Autism Center. <https://depts.washington.edu/uwautism/wp-content/uploads/2020/05/Ten-Tips-for-Discussing-Autism-with-Your-Child.pdf>





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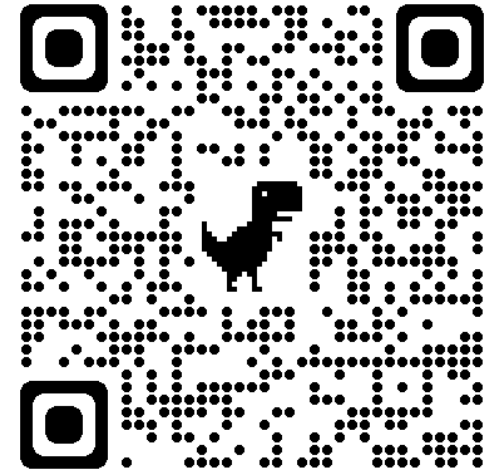
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