

# Deciding on Disclosure at Home

*Talking About Diagnostic “Labels” and  
Understanding How it Impacts Your Child & Family*

**Tracey L. Stoll, MEd, BCSE, ACAS**  
Executive Director

# Agenda

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- Introductions
- Should you tell your child they have a diagnosed disability?
- How/When can you talk with your child about his/her disability?
- Who can help you talk with your child about his/her disability?
- Related Resources, Q&A and Discussion

# Should you tell your child?

<https://www.merriam-webster.com/dictionary/disclosure>

## **Definition of disclosure** [for English Language Learners]:

- ❖ the act of making something known;
- ❖ the act of disclosing something;
- ❖ something (such as information) that is made known or revealed.

# Should you tell your child?

- In short: *YES*

- Most children sense if they are experiencing life differently than their peers
- Those around your child sense he/she is experiencing life differently than their peers

***Benefit***



- You have more control over the “messages” your child and others’ receive and understand about your child, if you explain his/her experiences.

# Should you tell your child?

- In short: *YES*

- Others know that a child may have special needs. It is not something that can be, or should be “hidden.”
- People often interpret “hidden” information as something that is negative, or a secret to be ashamed of.

## *Benefit*



- Telling your child introduces a positive tone early on to think of differences as a unique part of his/her self that adds to any classroom/community. Not to think of differences/challenges as something to be ashamed of/embarrassed of.

# Should you tell your child?

## ○ In short: *YES*

- If you don't tell your child, you risk someone else (peers, doctors, members of community, etc.) telling your child.
- Not telling your child does not change who he/she is, whether he/she has a diagnosis, what challenges may be, etc.

## *Benefit*



- Telling your child allows them to explore, develop and be open to learning self-advocacy needs and strategies.

# Should you tell your child?

## ○ In short: *YES*

- Not telling your child leaves cognitive and emotional space for your child to misinterpret why he/she struggles, and may fill in the “blanks” with self-deprecation.
- Not telling your child increases the chance of low self-image, low self-esteem and related side effects (depression, anxiety, etc.)

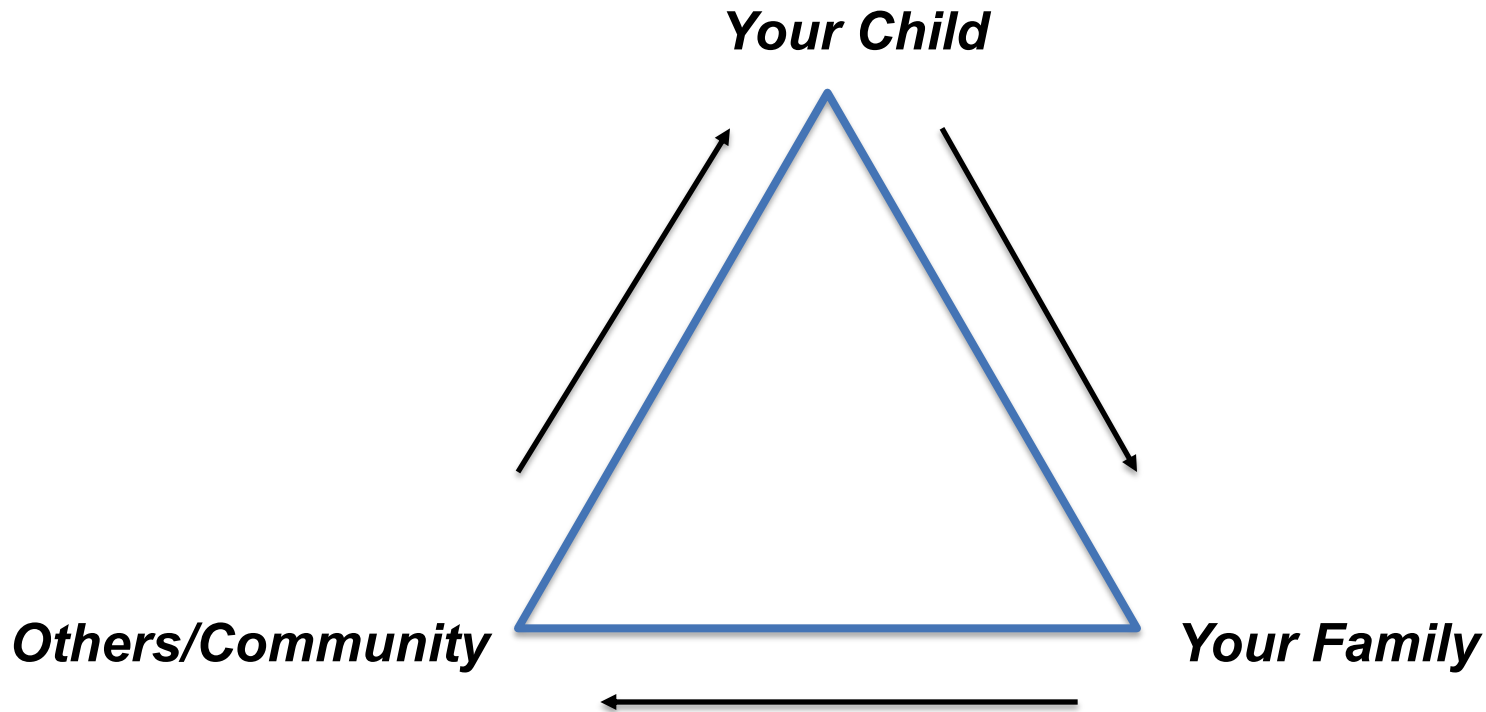
***Benefit***



- Telling your child empowers them to choose whether or not share their information with others, and how to answer uninvited questions that may come their way from others.

# Should you tell your child?

- WHO does this matter to, and WHY?





# How/When you tell your child?

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- Every child is different.
- Case-by-case basis driven by individual development (intellectual capabilities, medical needs, physical needs, language needs, social needs, etc.)
- Children often ask direct questions at different times/stages.
- “Double Digit” Rule of Discussion

# How/When you tell your child?

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- Ages 2-4 years old:
  - Do not need to use “label” vocabulary. (Not necessarily diagnosed in early years.)
  - Use concrete explanations of observable behavior.
  - Answer questions short and simple, if asked.
  - Model expectations and reinforce successes.
  - Provide love, nurturing, care and patience.

# How/When you tell your child?

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- Ages 5-7 years old:
  - Answer questions simple and concretely when asked.
  - Give only necessary information if/when asked.
  - Always emphasize strengths, and support challenges positively
  - Describe behaviors versus categorize with “label.”
  - Talk about the way “people” grow; “brains” grow.
  - Do not use negative or deprecating vocabulary.

# How/When you tell your child?

- Ages 8-9 years old:
  - Similar to earlier ages.
  - Provide a little more relative detail.
  - Consider leaving related “literature” or “role model” examples within environment.
  - Often will begin to ask “why” need to see doctors, therapists, different schedule, etc.
  - Most children by this age have begun to notice and “feel” different than their peers. Peers have noticed too.

❖ ***Be careful not to mistake/project your emotions, thoughts, fears about your child's challenges (diagnosis), onto your child.***

# How/When you tell your child?

- Ages 10-12 years old:
  - “Double Digit” Rule of Discussion
  - Typically an appropriate time to introduce “label” or diagnostic vocabulary (if have not prior).
  - Most likely child has realized their challenges and experiences are different than those of their peers. (emotions high and vulnerable.)
  - Some children have experienced peers commenting on their different experiences, strengths and challenges.

# How/When you tell your child?

- Ages 10-12 years old:
  - Continue to emphasize strengths, and support challenges positively – but be honest and acknowledge challenges truthfully
  - Introduce role models or people in history that have battled and succeeded with a disability.
  - If you have not already, seek outside professional support and help privately and/or through school.

# How/When you tell your child?

- Ages 10-12 years old:
  - Keep lines of communication open. Encourage questions.
  - Remember, children are savvy to the Internet!
  - Talk freely with family members in a positive manner.
  - Remember your child will go through multiple stages of emotions, understanding, denial, conflict, acceptance, etc. ***This lasts for years, not days.***

# How/When you tell your child?

- Ages 10-12 years old:

- Consider finding/identifying an affinity group (if have not already; the earlier the better).
- Help your child set small, obtainable goals of growth, and acknowledge when gains made due to perseverance.

“\_\_\_\_\_ is not an excuse. It's a reason to work harder. You can do this.”



# How/When you tell your child?

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- Ages 13+ years old:
  - Similar to earlier ages.
  - Child typically identifies as having different experiences than his/her peers and will continue to ride a roller coaster of emotions and thoughts about personal strengths and weaknesses.
  - Don't wait much longer. It may become more difficult to discuss/hear, and seem like a “secret” just learning.
  - Puberty has set in! Add this to the mix.

# How/When you tell your child?

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- Ages 13+ years old:
  - Remember YOU are the adult mind. Your child may become more resistant to talking, participating in services, being around peers.
  - Remember, they may have an emerging adult body, but they are thinking with an immature, vulnerable mind that continues to NEED adult boundaries and guidance.

# Who can help you talk to your child?

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- Professionals/Community:
  - Educators
  - Therapists
  - Service Providers
  - Community role models
  - Doctors/Specialists
  - In Home Therapy teams/Therapeutic Mentor/Support and Crisis teams
  - Community Associations, religious affiliations and/or support groups identifying with specific diagnosis/disability.

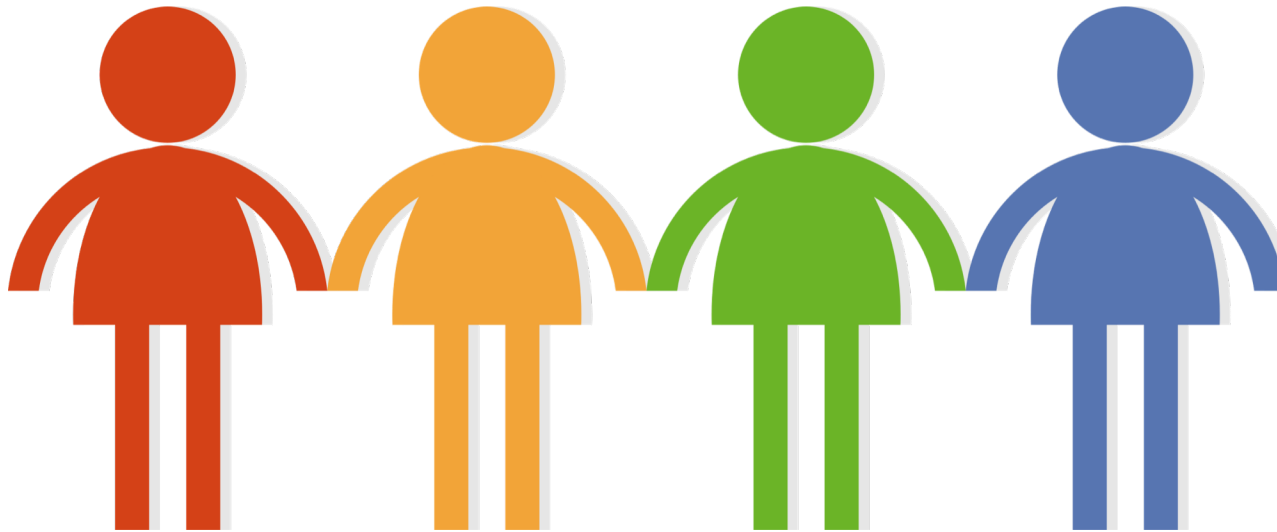
# Who can help you talk to your child?

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- Family/Friends:
  - Parents/Guardians
  - Siblings
  - Extended Family
  - Trusted, close friends

# Additional Resources, Q&A and Discussion

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# Thank You!

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**Tracey L. Stoll, MEd, BCSE, ACAS**

*Executive Director*

**Learning Solutions, LLC**

49 Walpole St., Suite 5

Norwood, MA 02062

781-762-3750

[info@learningsolutionsforme.com](mailto:info@learningsolutionsforme.com)

[www.learningsolutionsforme.com](http://www.learningsolutionsforme.com)