

## Disclosure: To Tell or Not to Tell

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- disclosure
  - the action of making new or secret information known
  - a fact, especially a secret, that is made known
  - something uncovered
  - making something evident
  - exposure; revelation
- Critical for both individuals with visible AND hidden disabilities
- Most of all, a PERSONAL decision

## Kinds of Disclosure

**Formal** - involves documentation/testing

- By professional to parent/patient or client
- By parent to school, agency, etc.
- By self-advocate to school, agency, etc.

## Diagnostic Interpretive

- When clinicians meet with the family after the evaluation process to discuss the findings from the assessments, any diagnoses and recommendations
- May have been first experience with *disclosure*



## Diagnostic Interpretive

- Parents never forget the feedback session
- May set the tone for the grieving process
- Best opportunity to:
  - Understand results
  - Receive professional guidance
  - Learn about next steps

## Kinds of Disclosure

### Informal

- By parent to family/friends
- By parent to child
- By parent to people in the community
- By self-advocate to people in the community

## Decision to Disclose

Every disclosure decision is personal and is based on:

- Understanding of diagnosis
- Acceptance of diagnosis
- Age of child and their understanding
- Severity of challenges
- How the child feels (confident, good about themselves, or embarrassed, self-conscious, excluded)

How will disclosing impact the child/adult

## Disclosure

- Disclosure is typically not a one-time conversation but a process and an ongoing dialogue
  - Need time to clarify and understand and process feelings
  - Need time to normalize that this is only one part of me/my child
  - Need time to reach acceptance and feel comfortable discussing

## Not an 'All or Nothing' Decision

- Don't have to tell everyone
  - Not everyone needs to know
- Don't have to give DSM-5 Definition of diagnosis
  - Give enough information that explains the child's learning needs/challenges for that particular situation
  - Give information that is understandable
  - Too much information can be overwhelming

## Disclosure to Family and Friends

- Often first experience with disclosing
- Disclosure at a very emotional, stressful time
- Who do you tell? What do you tell them?
- How do you tell so many people?
- How do you respond to the reactions to the news?
- Disclosure can change or impact relationships

## Impact of ASD on Relationships

- Study by the Interactive Autism Network (IAN) Project through Autism Speaks, 43% of fathers and 50% of mothers reported a negative impact on extended family relationships
- When it came to friendships and social networks, nearly 60% of mothers and fathers reported that having a child with ASD had a negative impact.

- Autism Speaks (2009) Interactive Autism Network Research Report: Family Stress- Part 3



### In a Perfect World...

- Family provides us with the help we need when we go through difficult times
- We can open up to our family about our fears, joys and know they will understand
- Our family accepts us no matter what, forgives our mistakes, loves us unconditionally
- They are our “safe place” to go when no one understands



### Obstacles to Developing Supportive Relationships with Family/Friends

- Confusion about the diagnosis and what it means for the family
- Parents may avoid talking about it, may not be honest about how things really are
- Parent’s reluctance to ask for help or accept help
- Negative first reactions- disagreement with diagnosis, assigning blame, making judgements, rejecting the child

### Strategies for Disclosing to Family and Friends

- Educate about the diagnosis and it’s impact on the child
- Involve family/friends in day-to-day life
- Share strengths, improvements, strategies
- Family and friends may need support too
- Be honest about what is difficult
- Family and friends typically want to help, so accept help or ask for help when needed

### Disclosure to Child

#### Why?

- Self-Advocacy/Self-Determination
- Need to know why things are difficult
- Often a relief to know
- Better to hear it from parent
- Keeping it secret – conveys a need to hide it
- Opportunity to control the first conversation
- Knowledge is power

### Self-Determination....



Refers to both the right and the capacity of individuals to exert control over and direct their lives

## To your child, self-determination means...

- Knowing and believing in themselves
- Knowing what they want their future to look like and how to plan for that future
- Knowing the supports they will need to have in order to have the most autonomy

## Encouraging Self-Determination

- Encourage your child to make choices about everyday activities
- Encourage your child to set priorities
- Help your child identify their interests, preferences and strengths
- Educate yourself and your child about rights

## Disclosure to Child

### When?

- Is child asking questions or recognizing differences?
- Will child be receiving extra support?
- Will child need to advocate for themselves?



## Strategies for Disclosing to Child

- Focus on the child and not the disability
- Balance the conversation to include child's strengths, talents, gifts, interests and learning differences
- Normalize through references to others with similar disabilities
- Use books, movies, TV shows that may help educate about disability

## Strategies for Disclosing to Child

- Begin discussion with the strengths, interests, and learning differences of everyone in the family
- Educate don't excuse:
  - Stress coping and learning strategies
  - Know that the expectations you have for your children greatly influence their achievements for themselves
  - Children with disabilities are often unmotivated due to feelings of failure, frustration and false labels

## Tips For Talking With Your Child

- “A picture is worth a thousand words.”
- Break information down into small steps
- Use as many resources as possible
- Stay positive
- Reach out to others for help



## Tips for Talking with Your Child

- Provide feedback for your child
- Praise progress and effort as well as results
- Give honest and specific compliments
- Provide corrective criticism when warranted
- Know that by talking to your child you are modeling skills they will need to be self-determined

## Community Disclosure

- Accommodations
- Legal protection
- Greater self-worth
- Opportunity for acceptance and inclusion
- Realistic expectations
- Greater advocacy
- Raises awareness
- Builds community of support



- Negative responses
- Relive trauma
- Possible exclusion
- Being treated differently
- Overlooked for advancement

## Disclosure to Helpers in Community

### When?

- At times of transition: new school, classroom, PSE program, job, new support staff
- Before, so helper is prepared
- Before problems happen- to prevent problems



## IDEA

### Individuals with Disabilities Education Act

- Young people with disabilities are *entitled* to a free appropriate public education (FAPE)
- 13 Categories of Disability
- IEPs
- BIPs
- 504 plans

## Strategies for Disclosure to Community Helpers

- Use a disclosure script
- Create an "All About Me" Book
- Offer disability resource materials
- Third party: e.g., an advocate, such as a job coach, requests assistance on behalf of an employee with a disability

## Disclosure to Community

- Educate and build awareness about the disability
  - School
  - Neighborhood
  - Police, Firefighters, First Responders
  - Faith community
  - Frequently visited places: Grocery store, movie theater, library, etc.
  - Employers is to develop community of support that knows and accepts your child

## Self-Disclosure

### Why?

- May want assistance or support
- To understand rights and responsibilities
- May want to give explanation for differences
- To alleviate stress related to “fitting in”
- To raise awareness and build support

## ADA

A person qualifies as having a disability under the **Americans with Disabilities Act (ADA)** if they meet at least one of the following three conditions:

1. A physical or mental impairment that substantially limits one or more major life activities
2. A record of such impairment
3. A perception by others as having an impairment (such as a person with a disfiguring facial scar, or a person rumored to be HIV positive)

## Self-Disclosure

### When?

- When starting in new environment
  - PSE
  - Job
  - Relationships
- When others have questions
- Before possible problems develop

## Strategies for Self-Disclosure

- Verbal
- Written personalized information sheet
- Offer disability resource materials
- Third party: e.g., an advocate, such as a job coach, requests assistance on behalf of an employee with a disability

## Not Alone in This...



## Be Assertive

- Stand up for your personal rights
- Express your thoughts, feelings, and beliefs in a direct, honest, and appropriate way
- Show respect for yourself and others
- Leave room for compromise
  - maintain good eye contact
  - express yourself clearly, stay on topic, and avoid apologizing or losing your temper

## Components of Disclosure

- **You can use general terms:** disability, medical condition, illness
- **You can be more specific but still vague:** a biological disorder, a neurological problem, a brain disorder, difficulty with stress
- **Or you can provide the exact diagnosis:** Down syndrome, multiple sclerosis, major depression
- Avoid using terms such as "chronic condition" and "permanently debilitating"
- Be brief and matter-of-fact when describing your disability

## Effective Disclosure

- Always present yourself as a capable individual who just happens to have a disability
- Disclose to the appropriate person
- Approach the discussion in a positive way
- Focus on what you CAN do
- Anticipate the reaction
- Play it straight
- Help others help you

## Sample Script

"I have a medical condition that sometimes interferes with my ability to \_\_\_\_\_. In a previous position, I found that \_\_\_\_\_ helped to minimize my problems in this area. I would like to discuss implementing a similar workplace accommodation here. I am confident that my experience, skills, and enthusiasm will enable me to perform the position of \_\_\_\_\_ successfully. I look forward to proving myself as a valuable member of your work team."

## Resources

- 411 on Disability Disclosure: A Workbook for Youth with Disabilities [www.ncwd-youth.info/411-on-disability-disclosure](http://www.ncwd-youth.info/411-on-disability-disclosure)
- A Clinician's Guide to Providing Effective Feedback to Families Affected by Autism: An Autism Speaks ATN/AIR-P Guide for Providers
- Cyber Disclosure for Youth with Disabilities <http://www.ncwd-youth.info/cyber-disclosure>
- Disability Disclosure Done Right, <http://www.softskillsbuilder.com/2016/01/disability-disclosure-done-right.html>
- Disability Inquiries In The Workforce Development System [www.ncwd-youth.info/information-brief-09](http://www.ncwd-youth.info/information-brief-09)
- DOL's Office of Disability Employment Policy [www.dol.gov/odep](http://www.dol.gov/odep)
- Autism Speaks (2009) *Interactive Autism Network Research Report: Family Stress- Part 3*.
- Job Accommodation Network [www.askjan.org](http://www.askjan.org)
- National Collaborative on Workforce and Disability for Youth [www.ncwd-youth.info](http://www.ncwd-youth.info)
- The 411 on Disability Disclosure: A Workbook for Families, Educators, Youth Service Professionals, and Adult Allies Who Care About Youth with Disabilities [www.ncwd-youth.info/411-on-disability-disclosure-for-adults](http://www.ncwd-youth.info/411-on-disability-disclosure-for-adults)
- Self-Determination power point slides were adapted from a PPT on Self-Determination [www.indetermined.org](http://www.indetermined.org)