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Disclosure Part 2: A Psychological Perspective for Informing the Community About A Diagnosable Mental Health Issue

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Disclosure Part 1

- What to say and how to say it- How best to talk to your child and the family about a diagnosed mental health condition.
- Dr. Lori Rockmore
- www.njcts.org
  - programs
    - webinar archives
      - November 2, 2016

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This isn't only a Tourette's Presentation

- Today we will be focusing on the various symptoms that come with TS. Not just tics, but the other facets of the diagnosis.
- However, this presentation could also apply to disclosure of non-neurological disorders regarding medical conditions, physical limitations, allergies, etc.

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Goals for Today's Presentation

- Discuss how to decide if you should disclose mental illnesses to the community
- Review the pros and cons of disclosing mental illness to the community
- Discuss when to disclose
- Discuss which members of the community/institutions should the mental illness be disclosed to.
- Review different ways to make these disclosures

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When to Disclose

- If the symptoms are obvious and not explaining would be more disruptive
- If the symptoms require special accommodations to function normally
- If the person with the mental illness doesn't want to keep a secret
- If the person with the mental illness wants to feel supported
- If the person with mental illness wants to help de-stigmatize mental illness and educate others
- If the person with mental illness wants to advocate for others

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When Not to Disclose

- If the person with the mental illness doesn't want to
- If the mental illness is not obvious to others
- If the mental illness does not impact the ability to function normally
- If there is reason to believe that the cons will outweigh the pros

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The Cons of Disclosure

- Concern about stigma
- Concern about bullying
- Possibility of being treated differently than others
- Possibility of being stereotyped and that others will only view you through the lens of the illness
- Lowered expectations from others
- A built in excuse for not trying hard or taking responsibility

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The Pros of Disclosure

- Don't have to live in fear of others finding out
- Ability to gain understanding and support from peers and community at large
- More likely to gain protection from peers and community at large
- Accommodations can be made that make it easier for the person with the mental illness to function normally across challenging situations.

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The Downside of not Disclosing

- In the absence of information, people will feel free to interpret symptoms however they like, but its more likely to be unfavorable.
- The longer you wait, the harder it can become.
- The person with the disorder might live in fear that others will find out.
- They may live in fear of how they might be treated when people do find out.
- Not disclosing takes a lot of your ability to control the situation out of your hands.
- Not disclosing makes it harder to get helpful accommodations.

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When is it time to disclose?

- If, and only if, the person with the illness is ready and willing to disclose
- When the symptoms are obvious to others and saying nothing could be more disruptive in the long run
- When others not knowing leads to being misunderstood and mistreated
- When its time to ask for reasonable accommodations
- When the anxiety of others finding out becomes disruptive to normal functioning.
- If the person with the mental illness and the family want to be preemptive

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Timing disclosures

- Ideally at the beginning of a school year
- When joining a new group
- The beginning of a new sports season
- The start of a new friendship
- Whenever

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Who to disclose to?

- Trusted members of the community
- School faculty and staff
- Group/Team/Community leaders
- The whole group/community

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How to Disclose

- Start selecting trusted people to disclose to, educate them, and empower them to tell others
- Meet with and educate a community/group/team leader and plan together to address and educate the group
- Have an experienced clinician meet with a group to provide a workshop or peer inservice
- Have the person with the mental illness prepare a presentation
- Social Media

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Case Example #1

- Sally is a 10 year old who is a member of the Girl Scouts. She has Attention Deficit/Hyperactivity Disorder (ADHD), Combined Type. She is not on medication. She is outgoing, energetic, motivated and always the first to volunteer to help. However, during meetings she has a tendency to blurt out her ideas, sometimes interrupting others. She can also be a bit hyper and has difficulty sitting still. Her peers get annoyed with her in these situations and even the troop leaders sometimes slip and openly express their frustration through body language and passive aggressive comments.

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Intervention #1

- Sally's mother explained to the troop leader that Sally has ADHD and explained her reasons why the family has not decided to medicate her.
- She also points out some situations where Sally has reported or her mother has witnessed unkind behavior towards her daughter. The family is not requesting that anyone be disciplined for this.
- Sally's mother shares information with the troop leader about accommodations for ADHD.
- The troop leader suggests that this is an excellent opportunity to teach the other scouts about differences. Sally volunteers to give a presentation on ADHD at the next scout meeting.
- This opens up future conversations from other troop members about ways in which they are different.
- The troop meetings now allow for more movement during meetings and presentations. Troop members now know how Sally would like to be helped and offer it when necessary.

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Case Example #2

- John is a 15 year old with religious Obsessive Compulsive Disorder (OCD). His OCD causes him to frequently engage in frequent prayer rituals that he believes have to be done perfectly or god will be offended and he will go to hell. The compulsion is triggered when he thinks he had an 'inappropriate thought' or that he may have done something to offend god. His rituals are mostly mental so most people don't know when he's doing them. He is resisting exposure and response prevention therapy because he believes that if he doesn't give in to his OCD he will offend god (who may be the one asking him to do the rituals) and will go to hell.

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Intervention #2

- The family contacted the priest that John likes the best from his church, Father Bill. Father Bill collaborates with John's therapist who educates Father Bill about OCD and its treatment.
- Father Bill meets with John to discuss fears that John has that seem to be more based in OCD then any actual beliefs his church or religion subscribes to.
- Father Bill and John's therapist collaborate on exposure exercises that would not be considered to be in violation of the church's teachings.
- Father Bill and John do some of the exposure exercises together, sometimes in the church.

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Case Example #3

- Eddie is a 3rd grader with Tourettes Syndrome. His main motor tic is facial grimacing that causes him to have an exaggerated smile or a scrunched up face. Sometimes, maybe once or twice a day, his vocal tics will cause him to make gulping noises or a series of squeaks that are very noticeable, especially during tests. His teacher knows he has Tourettes and is good at ignoring the tic. Eddie doesn't react much when he has a tic because he's used to them and his family doesn't seem to mind much. Classmates shoot him dirty looks, reprimand him, or laugh. The teacher tells them to mind their own business. They make fun of him behind his back, but he's caught them imitating him, on occasion. They are starting to exclude him during lunch, recess, and afterschool.

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Intervention #3

- The teacher makes the family aware of the situation but feels like her hands are tied because she doesn't have the family's permission to disclose his condition to the class.
- The family seeks advice from the New Jersey Center for Tourette Syndrome and Associated Disorders (NJCTS) and because they are brilliant and awesome, they send in their most amazing and handsome presenter, a Doctor who works in East Brunswick who will remain unnamed but he's super cool.
- Dr. Zambrano…oops, I mean the doctor who will remain unnamed goes into the school and does an in-service for the faculty of the school and a peer inservice for the whole third grade.
- Eddie volunteers to be introduced at the end of the peer inservice and answers the 3rd graders' questions.
- A mean kid cries. An angel gets his wings.

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Case Example #4

- Paula is 14 years old. She's had very mild tics for many years that no one ever noticed, therefore there was no apparent need for disclosure. She's a bit of a late bloomer but with the onset of puberty her tics became more noticeable (mainly twisting her body and abdominal tensing). At school nobody seemed to notice but in gymnastics, which was very competitive and where her coaches were very strict, the tics were worse. She was having an increasingly difficult time controlling the tics and she was very afraid that others would notice, so she started to miss a lot of practice and was close to being kicked off of the main squad. Most of the other competitors didn't go to her school. She decided to quit gymnastics.

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Intervention #4

- Her parents were encouraged not to force her to go back until she was ready
- A less intense gymnastics program was considered, because it was believed that anxiety exacerbated her tics
- We discussed the benefits of disclosing her Tourettes to her teammates. We started by telling close friends she could trust to see how they would react. From there she started to be more open about it with her classmates.
- She chose a different place to do gymnastics, but shared details about her TS with some of her old gymnastics friends, one of whom switched to the new gym, too. She gave them permission to tell others, if they wanted to or were asked.
- She immediately disclosed to the new gym what her symptoms were so that she wouldn't be so afraid of others finding out. She was better able to focus, she actually had fewer tics, and she really blossomed as a gymnast in the new situation.

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Questions?

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