IDENTIFYING BARRIERS: SUPPORTING INCREASED OWNERSHIP

Slide 1
> Title Page

Slide 2
> These slides should promote discussion/reflection about the subjects being described. There will be guiding questions to promote this engagement and discussion.

Slide 3
> Set this as your intention for following the slide deck. If you don't learn it, please reach out to Tourette Canada for more information.

Slide 4
- This presentation starts by exploring disability in general. It will later focus in on Tourette Syndrome.
- Social barriers can be created by well-intentioned and well-informed individuals. It's important to continually question actions and practices in order to stop inadvertently creating barriers.
- There's a lot of talk in social model disability circles about identifying barriers and accommodating for those barriers (or removing those barriers).
- In attempting to remove barriers for individuals, sometimes we can remove that individual's ownership and independence
    - EX. Look at these images:
        - In the first image, a barrier has been created that is impeding the young child's view of the ball game.
        - In the second image, an accommodations has been put in place to help the young child overcome this barrier.
            - This child had no ownership over his own inability to see the game. He had to rely on the the tall man to give up his own box.
        - In the third image, the barrier has been removed
            - This is ownership, the young child doesn't need anybody to support them because they can support themselves
- More important than removing barriers for individuals is helping individuals identify their own barriers and providing those individuals with the tools necessary to remove barriers for themselves.

Slide 5
- We may enter the lives of individuals with disabilities as allies (supporting the individual with a disability to use their own voice) or advocates (using your voice to express the best interests of the individual with disabilities).
    - An ally might mean listening, supporting, encouraging, or simply being with an individual with a disability.
- We know who we should be for the individual with a disability by engaging with them and listening to them.
- Individuals with disabilities may not tell you outright that they want you to be an ally or an advocate, but they may let you know through words and behaviours – simply listen.

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- The important part to keep in mind when thinking about the advocate/ally spectrum is that there will always be movement on the spectrum. It's not always a movement in one direction, and it's always going to be based on context of the moment. It should always be led by the individual with a disability.
- Beware of "over-advocacy," which may turn into dependency. Also beware of diminishing the experience of an individual with a disability. This can leave individuals feeling unsupported.

Slide 6

I approach my work with individuals with disabilities from these four perspectives.

Slide 7
- Here the presentation moves from general discussion about disability into specific discussion about TS+.
- Some of the material presented here will be from _my_ first-person experience as an individual with TS+:
    - This is only one of many experiences and representations of TS+.
    - Do not be tempted to generalize my experience with all TS+ experiences.
- Supporting individuals with TS+ may take a great deal of being present in the moment, holding space to allow them time to express themselves, creating universally designed learning assessments and classroom delivery for youth with TS+, and supporting the functional impacts of the individual with TS+ as opposed to relying the diagnosis of TS+ (i.e., "I know how people with TS+ behave.")

Slide 8 & 9

A very brief description of the M.Ed research that I have recently (2016) undertaken.

Slide 10
- Before going too deep into what I learned from my research – let's look at some literature I reviewed.
- All three books contained some aspect of the main character (who in all three books had TS+) taking ownership of their own TS+ experience.
- With TS+ comes a lot of internalized social barriers. In all three books, the characters speak about feeling ashamed of their TS+ and not knowing how to talk about it or share it with others. In all three books, the protagonist delivers a presentation to their class.
    - **Hi, I'm Adam** – urges everybody to "learn about [TS], then teach others about Tourette Syndrome"
    - **Tic Talk** – a 9-year-old boy is afraid that people will find out about his TS. Finally he delivers a presentation about TS to his class and realizes that "it was just another day." His mother noted that he "was having very few tics." [TS and Stress]
    - **Ticcing Thomas** – When the protagonist of this book delivered a presentation to his class, he was surprised to find that "some of [his] classmates even told me about some of their problems too."

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- All three of these books demonstrate that "holding of space" for individuals with disabilities to address their own social barriers has huge positive impact to the individual's self-worth.

Slide 11

Discussion/reflection opportunity.

Slide 12
- These four images are taken from an activity I did with youth with TS+.
    - Figures 1 & 2 demonstrate feelings of rejection leading to loneliness
        - FIG. 1 – External voice (or internal voice) – Potential example of social rejection felt by the drawer
        - FIG. 2 – Internal voice – Effect that was perhaps caused by the voice in
    - Figures 3 & 4 demonstrate feelings of loneliness turning to anger.
        - FIG. 3 – Internal voice – Pictorial theme continues (crying face). This one has DEFIENCE. Sadness (perhaps caused by loneliness) turned to anger.
        - FIG. 4 – External/Internal voice – Anger directed at personified TS+ - perhaps TS+ is reason for social rejection?

Slide 13

- Please check out www.tourette.ca to learn more about TS+.--

Alan Jeans - 2016