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DISCLOSURE OF DIAGNOSIS - Across Development

presented by Rose Freigang

LDAO Family Conference

October 19, 2019

What do we mean by disclosure?

For parents it means letting your child or adolescent know that they have “an identifiable, common, measurable, and treatable condition.” Frustration, self-blame, and low motivation may be avoided or reduced when a student has a basic understanding of their learning challenges. If there is less confusion or worry about learning problems in the classroom, there is more energy for learning.

Disclosure at school, college, university or the workplace means an approach to inform an instructor, counsellor, employer (potential employer) of a disability that needs to be addressed and accommodated. A “hidden disability” like an LD, ADHD or mental health problem does not need to be disclosed; however, without declaration of a disability the organization or institution will not be aware of the need to accommodate. In Ontario, these all qualify as disabilities (according to the Ontario Human Rights Commission) for which reasonable accommodations (i.e., those that do not cause “undue hardships” to the facility in terms of expense or operations) need to be provided. The timing and the content beyond what the disability is at the discretion of the individual. The expectation of confidentiality remains a right of the individual.

Elementary School

Starting point for disclosure is at the **beginning** of the assessment process before your child has even met the practitioner who will be doing the assessment. Typically, the first session is with parent(s)/or caregiver(s) to obtain a history and to pin down the questions you would like to have answered by the assessment. If you are uncertain about how to describe the process, ask your psychologist or psychological associate for some guidance.

You can set the stage for “buy in” with the process by offering a straightforward explanation that is geared to your child’s age and way you understand he/she takes in information. Using a metaphor (e.g., sports team with different members playing a role; science/detective team collecting information to figure out a mystery; family working together to put together a puzzle, build something, make a meal etc.) that your child might relate to can be helpful. It will be important to put forward the idea that you, your child, the school and the person doing the assessment **will be working together**.

Briefly describe what you know will happen (e.g., doing different activities) and when – letting your child know through your body language, facial expression, and words that you have



insight psychology and that you trust and like the person they will
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be seeing. If you have worries about how your child will do with testing, discuss this in advance.

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with your psychology professional. You can let them know things that will set them at ease, help them manage fidgetiness and focus, improve co-operation etc.

Some children will like to know lots of information, and others will not. Both responses are OK and may reflect personality differences in how they adapt to new situations or cope with stress. Answer his or her questions clearly – keeping in mind the general parenting advice about other “tricky” topics like sex – just answer the question being asked. If you don’t know the answer to a question, let your child know you will find out or that you can ask at the first session.

Even if you have done your best to set the stage, some children will not remember what you told them. Don’t worry or be embarrassed when you meet the practitioner – this happens a lot – and he or she will go over the basics and fill in any gaps.

After the assessment is completed, the feedback will be shared with you in an interview and in written form with a report. This can be a long meeting with lots of words! Sometimes when children reach 10-12 years of age, they may be given the option of attending all or part of this. Many clinicians will offer a mini-feedback with your child as well – tailored to their attention span, tolerance for the “spotlight”, and vocabulary and comprehension. Visual tools may be used to support the presentation, and they may be given a summary sheet to take home. This can be an important process, not just for **what is said** but also demonstrate **respect and appreciation** for the child’s involvement. Again, we are setting the stage for them to be involved in their education and ultimately their ability to advocate for themselves.

The concept of LD can be difficult for a child to understand because it can be complex and subtle. Children often draw a **direct line** between struggling at school with something like reading or math and being “stupid” or “not as smart as others.” Unfortunately, they have also had this idea reinforced by others’ comments. By the time a child reaches the age of seven or so, he or she has become much more “tuned in” to how they compare with others – they pay attention and notice. All of this can make the idea of being intelligent and even sometimes having special talents, but not being able to read or spell as well as most kids, very difficult to grasp. It may take a while, and lots of experiences (especially if a child’s sense of competence has been challenged or discouragement has started to set in).

A simple explanation is usually the best, and information does not need to be provided all at once. Rick Lavoie, in an article on the ADDitude website, highlights a few important details to include in your ongoing discussion:

- Remind your child that they are capable of learning (you can give clear examples of this in a variety of situations from school or outside of like athletics, music, art etc).
- Explain that they learn in a way that is unique to them, and may require them to participate in activities and programmes that are different than those of their peers or siblings.
- Their unique learning style will pose challenges for them with some activities, and so it take them longer to master some skills. They may need to keep trying, and stick with things before feeling

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like they are successful. Reassure them that they will “finish the race” but they may need to take a different route to get there.

- Their learning disability or difference is not their fault, and they have the support of home and school.

Putting your child’s “profile” in the context of all people of all ages having *preferences* in the way they learn can be helpful. The LDAO Soar booklet also describes this can be referred to as a *learning style* and refers to different modalities – reading, listening, doing, watching, and talking. There are also *learning abilities* – strengths and weaknesses. The psychoeducational assessment should have provided information about both of these areas. When describing this you might want to share your own experiences and self-reflection on your style/abilities. You might ask your youngster to give their opinion of what they’ve noticed about you (if you’re brave!) re: learning.

You can also talk about struggles you experienced growing up (or even as an adult) learning how to do something. Those of us who have not grown up as digital natives are not nearly as technologically savvy, or skilled at videogames as our children – so this can be a good example. You can use this to talk about how you cope!

Including conversations with your child about their strengths can be helpful as well, but it will be important to “keep it real.” Children are pretty good detectives when it comes to false compliments, or exaggerated reactions to accomplishments. A list of strengths in different areas has been provided to help you have this conversation, and maybe even broaden your perspective on characteristics and skills that should be noticed.

One of the most important aspects of this discussion is what will happen now to make things go more smoothly in the future. Emphasize working **smarter not harder** – sometimes children think they are going to have to spend even more time with school work. Here, you can talk about leveling the playing field by removing obstacles to learning (e.g., too much printing on a page), changing the way a subject is taught/explained, offering some strategies/tips/tricks to learning subject matter (i.e., toolbox), providing access to technology. Engaging your child, if they are ready and able to do this kind of problem solving, in the discussion of what they think might help is ideal.

You can mention or discuss how research is showing us that the brain continues to develop throughout or lifetime, and that it can change by using it and “exercising” it by trying new ways of learning and practicing. New connections can be made – there is hope that things will get better.

Talking with your son or daughter about privacy, and that they have control over who to share information with will be important. This can be especially important for a youngster who may lack “filters” or who acts impulsively. Also, respecting their need for confidentiality within the family and among other adults is your obligation.

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The role of effort (vs. making attributions related to traits) should be an underlying theme moving forward. Similarly, LD needs to be framed as an **explanation** for what is happening with regard to learning, but not as an **excuse**.

Knowledge is power.

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High School and Beyond

Students with a diagnosed LD, even those who may have been relieved to understand why they were having academic problems as a younger child, may struggle to acknowledge their continued difficulties as they transition into secondary school or college/university.

The desire to “fit in” and belong with their peer group trumps the potential benefits using assistive technology or seeking academic support. Concerns about being or looking different from the mainstream can be very strong. Fears that they *are or may be perceived* as “stupid” may resurface with a vengeance.

Another developmental task for teens and young adults is to establish their independence from parents and other adults. Sometimes this translates into wanting to try to succeed without anyone’s advice, support, or practical help. Attempts to provide the aforementioned assistance may be met with anger and rejection.

Practical roadblocks may interfere with seeking assistance. For example, students with a nonverbal LD who have visual-spatial deficits may have difficulty navigating the larger high school or university environment. They may get frustrated trying to find the student success centre and give up. Similarly, the need to move quickly from one class to another may challenge the student with slower processing speed to formulate his/her thoughts quickly enough to ask a teacher or instructor for help at the end of class.

Expectations for self-advocacy and independence in secondary school can be dramatically different than in elementary school. Implementation of an Individual Education Plan (IEP) can look very different, and requires more effort from the student (and parents). There tends to be less oversight and monitoring by individual teachers, or the school’s resource staff. Special education resources are offered, teachers (especially in math/science) regularly offer extra help during lunch hours/after school, librarians can be a great resource for accessing resources for projects – but the student needs to take the initiative in using them

For college/university, documentation is required to verify the LD and *the student must him or herself initiate contact with the student success centre* to access accommodations and other supports. No one will seek them out!

Anxiety, a not uncommon cousin to an LD, about approaching a teacher or instructor may prevent students from disclosing the need for accommodation or extra help. This may result in delay/avoidance, procrastination with assignments, and becoming overwhelmed by mid-semester.

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How you can help now and in the future....

Start early and revisit the LD issue often throughout a student's educational career. Create a shared vocabulary for discussing learning differences and style. Respect your son or daughter's privacy within and outside the family. At the same time, it is important to keep the LD diagnosis in its place – it is a part of, but does not define who your child is!

Share your own experiences with formal education/learning as well as your own self-awareness of strengths/weaknesses. Invite them to help you solve problems that allow them to demonstrate their knowledge and competence (e.g., digital technology, mechanics, drawing etc.). Link their help to their *strengths* (e.g., skill with tools) and *effort*.

Model asking for help/clarification, running into a roadblock and working through it, coping with disappointment/frustration, self-advocacy.

Involve students in outside activities that focus on their strengths and interests.

Your role needs to shift from *director* to *facilitator* as your child moves into adolescence and young adulthood. Provide the tools for success. Be there for encouragement, problem-solving/trouble shooting, and the provision of an environment at home that is conducive to learning (whatever that means for your student's preferred learning style).

“Outsource” homework/assignment completion, if it becomes too fraught with emotion and conflict.

Involve the student in school meetings about their IEP or other relevant issues (timing will depend on your student's maturity/readiness). Prepare them for meetings by reviewing what the agenda will be, discuss their role (e.g., observer/listener, self-advocate), chat about what issues they would like to raise or have you mention in a meeting.

Demonstrate to your student that you value education through your own actions. At the secondary school level, participating in school council can help to keep you informed about resources available, deadlines (e.g., application for special programmes like CELP or admission to postsecondary), and programmes that may be of value to your student. Often such information resides in the bottom of knapsacks. It can help you develop supportive relationships with other parents as well.

Help your student translate their learning differences, skills and interests into everyday behaviours and experiences.

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We live in a culture that can set people up for unnecessary disappointment and feelings of failure by suggesting that you can be anyone or anything you want. Very few talented and competent teenage hockey players make it to the NHL. Always have a plan B or plan C.

Support your student to set *realistic* goals for postsecondary education and career. Although it is important to dream big and think about many possibilities for the future as a young person; supporting a dream that is outside the realm of possibility does not do your child any favours. If your student has really struggled to obtain credits in science – even with appropriate supports and accommodations; then becoming a vet is not likely an achievable goal. Becoming a vet tech, however, may be.

Participation in summer jobs, volunteer opportunities, and co-operative learning experiences are a great way to help your student make decisions about what they would like to do in the future without having to make a longterm commitment. They can learn some of the “soft skills” – time management, following direction, customer service etc. – here as well.