

# Mental Health and IDD

We know that the chance of having a mental health problem when you have an intellectual or developmental disability (IDD) is higher than it is for other people. Caregivers play a very important role in identifying mental health problems as they emerge and in helping to do something about it.

It can be hard for people with IDD to talk about what is going on in their thoughts or even to express their feelings. Sometimes all we see from the outside is behaviour. Some people call this problem behaviour, aggression or challenging behaviour. Those words describe what we see, but not what is behind what we see. Also, these sorts of words suggest that the person has a problem, like there is something wrong with them that needs to be fixed. Another way we could describe these behaviours is by calling them “behaviours that challenge.” When we say “behaviours that challenge”, what we are really saying is that person is telling us that there is something not right for them THROUGH their behaviours. And these behaviours, whatever they are, are challenging for us to handle. Talking about it this way reminds us that the behaviours themselves may not be the problem. It is just as much about the environment, the situation, and our own expectations.

## What can you do to HELP?

There are four main things that can be helpful to know more about when we are trying to understand and promote the mental health of our family member: H-E-L-P (health, environment, lived experiences, and psychiatric disorders or concerns).



**Health** – Believe it or not, many of the problems we think are either behaviour problems or mental health issues are related to health issues that are not being picked up, even with regular doctor visits.

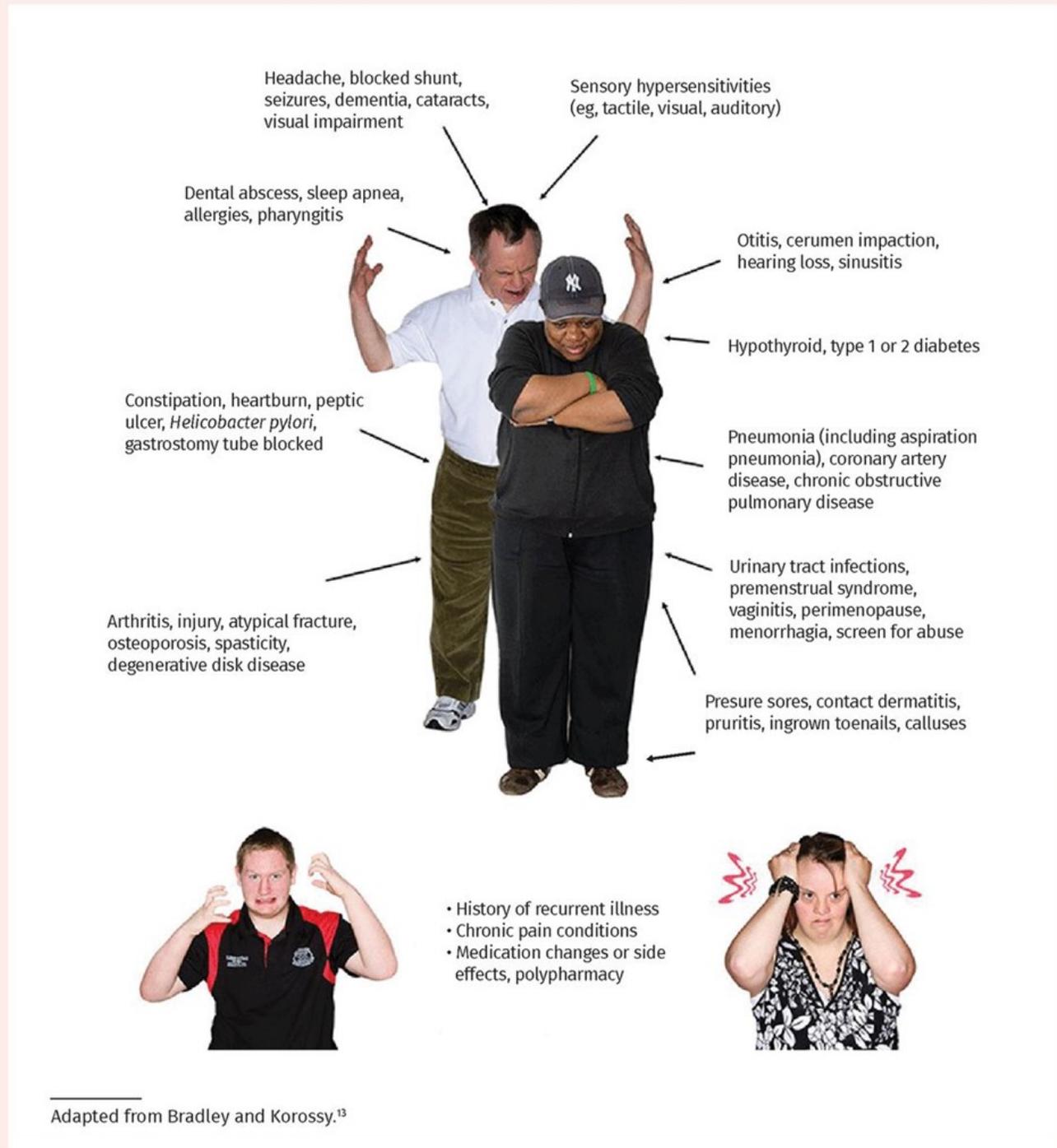
Imagine being in pain and nobody knows how much it hurts. What would you do to get the help you needed?

The diagram on the next page reminds us of many parts of the body where there could be pain or a health issue that might be missed. Before professionals start diagnosing or treating “behaviours” as though they are a mental health problem, we need to step back and think about a person’s health.

Start at the head, think about hearing, vision, and teeth, then work your way down the body all the way to the skin on someone’s feet, or ingrown toenails.



**Figure 2. Health conditions causing behaviours that challenge**



Green, L et al., (2018). HELP for behaviours that challenge in adults with intellectual and developmental disabilities. *Canadian Family Physician*, 64 (Suppl 2) S23-S31.

If your family member was in pain right now, how would others know? What are they usually like when there is a fever, or after hurting or cutting themselves? Could there be any side effects of medications that might be making things more difficult for the person? This could include dizziness, sleepiness, a fast heartbeat, dry mouth, stomach upset or nausea, constipation, or the need to move around a lot (akathisia). Knowing what these health issues are and doing something about them is always the first step.



**Environment** – Behaviour always happens somewhere, so we have to look as closely at what is going on around the person.

Sometimes an environment can feel stressful. There may not be enough support to help a person do what they need to do and that can be frustrating. An environment might become boring or dull because of lower expectations of what they can do. We may find that we do things for our loved one leading to a reduction in independence and potential increased feelings of incompetence. An environment might be disruptive, noisy, or unpredictable. Some people are able to manage well in this sort of situation, while others are not. So the next step is looking closely at the physical space the person is in and the emotional space. How can we make it more supportive, to match their needs?



**Lived experiences** – We know that many stressful and sometimes very traumatic things happen to people with IDD. What looks to us like a behaviour that challenges might be a response to a very difficult event that a person continues to struggle with.

Common life events that can lead to a lot of stress include the death or illness of a loved one, being bullied or teased or abused by someone, changes in staff where the individual may work or live, and changes in a favourite routine or activity. For people who can't understand why something bad has happened, it can be especially hard. It can also be hard when someone does not have a good sense of time. Something that happened a long time ago may still be very upsetting, like it happened yesterday. We might think it is better to pretend upsetting things didn't happen but that doesn't make the feelings go away.



**Psychiatric disorder or concern** – Just like people who don't have an IDD, those who do can also have psychiatric problems like depression or serious anxiety. Those sorts of things can be diagnosed and treated by a mental health professional after we have thought through H, E, and L.

There is important work for caregivers to do to support the individual prior to a problem becoming serious. Regular health check-ups, management of pain, and ensuring that eyes, ears and bodies are working well are all important. When something upsetting happens, caregivers can be there to provide support. Even when things seem okay, they can encourage healthy relationships, and make sure there are interesting activities happening that are not too stressful. Caregivers can't stop stress altogether, so it is important your loved one learns how to cope and manage stress in their lives. This includes helping them to find a way to communicate their needs and showing them that we are listening.

### Other resources:

- Free MindEd Online Course on Supporting Adults with Developmental Disabilities with Mental Health Concerns or Behaviours that Challenge: [https://www.minded.org.uk/Catalogue/Index?HierarchyId=0\\_41284&programmeld=41284](https://www.minded.org.uk/Catalogue/Index?HierarchyId=0_41284&programmeld=41284)
- “Let’s Talk about Mental Health and Developmental Disabilities” edition of The Direct Support Workers Newsletter: [http://www.vitacsls.org/UserFiles/uploads/files/Vita\\_Newsletter%20V5\\_2\\_Links\\_FINAL.pdf](http://www.vitacsls.org/UserFiles/uploads/files/Vita_Newsletter%20V5_2_Links_FINAL.pdf)