WHAT DOES IT MEAN TO HAVE AN INVISIBLE CONDITION?

EDITED BY: Eilidh Cage and Danijela Serbic
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WHAT DOES IT MEAN TO HAVE AN INVISIBLE CONDITION?

Topic Editors:
Eilidh Cage, University of Stirling, United Kingdom
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There are many people who experience invisible, and often undiagnosed, disabilities and conditions which affect their everyday lives. On the surface, it might not be immediately obvious that someone perhaps has a different way of thinking, experiencing or processing the world around them. Having an invisible disability usually means that it is difficult to provide concrete, visible evidence for it and it can be perceived as 'not real' by other people. Indeed, some individuals can often be made to feel they are not good enough, and may end up masking or hiding their difficulties in order to just get by in day-to-day life without being judged.

In this collection, we introduce and educate Young Minds about a range of "invisible" conditions, for example mental health conditions like Post-Traumatic Stress Disorder, autism, chronic pain conditions, intellectual disabilities, stuttering, and many others. We also highlight some of the wider challenges faced within society, such as the lack of understanding from other people, and discuss how Young Minds can potentially support their friends and family who might be experiencing some of these disabilities or conditions.

This collection covers what Young Minds could learn about what it means to have an invisible condition and how it can impact on relationships, education, thinking, communication, emotions, behaviours, and generally navigating everyday life. Further, some people might be unwilling to seek help and share their concerns with others, because they are worried that others don't really understand what life is like for them. We hope that this collection helps those without an invisible condition to think carefully about how they can make the world a more supportive and inclusive place for everyone.

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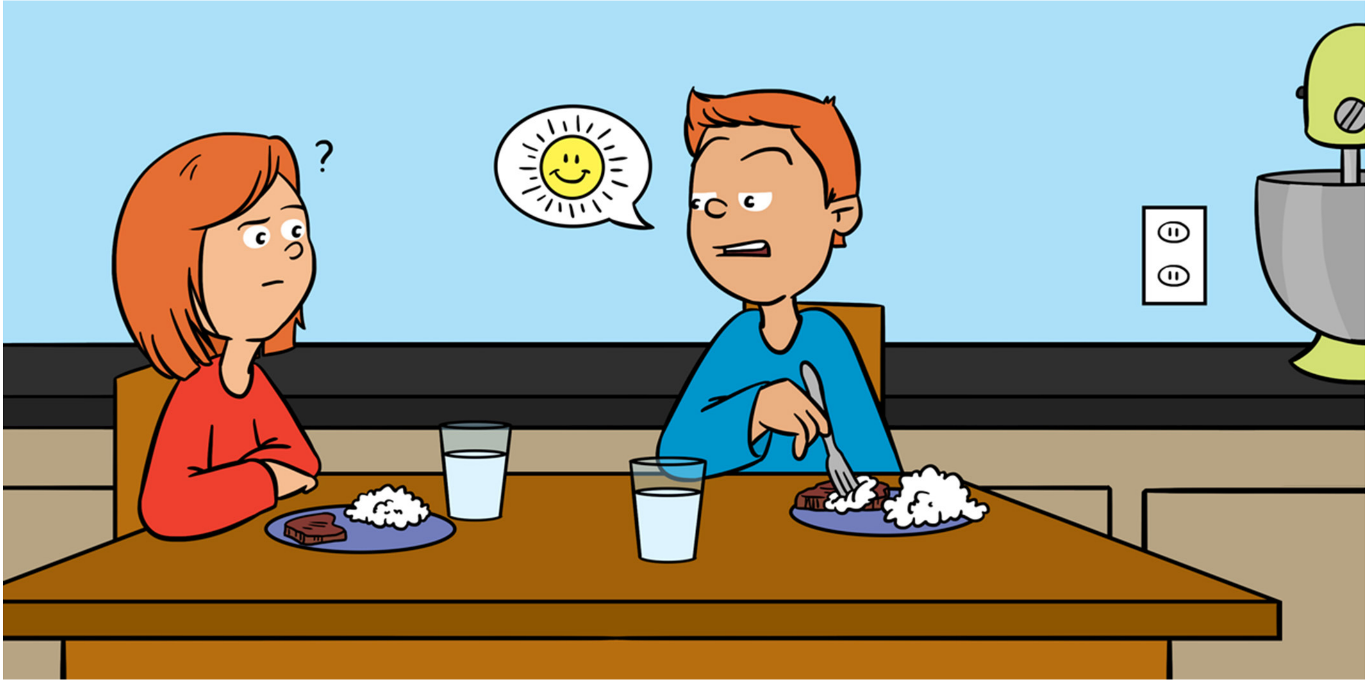

DOUBLE EMPATHY: WHY AUTISTIC PEOPLE ARE OFTEN MISUNDERSTOOD

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YOUNG REVIEWERS:


AMELIA
AGE: 15


ANAND
AGE: 13

Autism affects how someone makes sense of the world around them. About 1–2% of people are autistic. You might have an autistic classmate or family member, or maybe you are autistic. Autistic people might communicate differently than people who are not autistic. This means that it can be difficult for other people to understand what autistic people are trying to say or what they mean. We tend to think that people who are not autistic might be more successful at understanding other people, but in fact, autistic people may be better understood by other autistic people. We will examine and explain some research that has explored how autistic and non-autistic people communicate with each other and explore how this research fits with a theory called the double empathy problem. Understanding what makes interaction comfortable and easy for different people can help us all understand each other better.

WHAT IS THE DOUBLE EMPATHY PROBLEM?

Can you tell when somebody is bored or frustrated or upset with you, even when they do not say so? People often communicate information about themselves without even saying a word. The expressions on their faces or the ways they are acting can be big clues to what they might be feeling or thinking. Being **autistic** affects how people make sense of the world around them, and some autistic people can find it hard to communicate. For a long time, research has shown that autistic people can have trouble figuring out what non-autistic people are thinking and feeling, and this can make it difficult for them to make friends or to fit in. But recently, studies have shown that the problem goes both ways: people who are not autistic also have trouble figuring out what autistic people are thinking and feeling! It is not just autistic people who struggle.

A **theory** that helps to describe what happens when autistic and non-autistic people struggle to understand each other is called the **double empathy problem** [1] (Figure 1). **Empathy** is defined as the ability to understand or be aware of the feelings, thoughts, and experiences of others. According to the double empathy problem, empathy is a two-way process that depends a lot on our ways of doing things and our expectations from previous social experiences, which can be very different for autistic and non-autistic people. These differences can lead to a breakdown in communication that can be distressing for both autistic and non-autistic people. It might sometimes be difficult for non-autistic parents to understand what their autistic child is feeling, or autistic people might feel frustrated when they cannot effectively communicate their thoughts and feelings to others. In this way, communication barriers between autistic and non-autistic people can make it more difficult for them to connect, share experiences, and empathize with one another.

Let us look at the example of "reading between the lines." This is when you understand something that someone means, even when they have not said it with words. For example, your friend might say that his day has been okay, but sigh and seem a bit grumpy or sad. Reading between the lines, you might guess that your friend's day has not been okay at all. Autistic people might struggle to read between the lines of what non-autistic people are saying, because this way of communicating does not come easily to autistic people. On the other hand, non-autistic people might make incorrect assumptions about autistic people because they are reading between the lines too much.

Autistic people can find it exhausting and confusing to understand non-autistic ways of communicating. Likewise, non-autistic people might feel uncomfortable when they are around autistic people because their usual ways of communicating do not work as well. This

AUTISTIC

Being autistic is considered clinically to be a medical condition, but is also a source of social identity. Being autistic affects how someone makes sense of the world. Some autistic people can find it hard to communicate with other people, and might have difficulty making friends and fitting in. Autistic people might find changes difficult and might experience sounds, smells, and other senses differently. Some autistic people might move in a certain way (like twirling) or do the same thing repeatedly (like opening and closing doors). People are born autistic and remain so their whole lives. Some autistic people need only a little support, while others need a lot of help with learning and everyday activities.

THEORY

An explanation for how things work and why they happen. Scientists develop theories based on observations of the world and then test these theories using research studies.

DOUBLE EMPATHY PROBLEM

A theory that helps to describe what happens when autistic and non-autistic people struggle to understand each other.

EMPATHY

The ability to understand and share the feelings of another person.

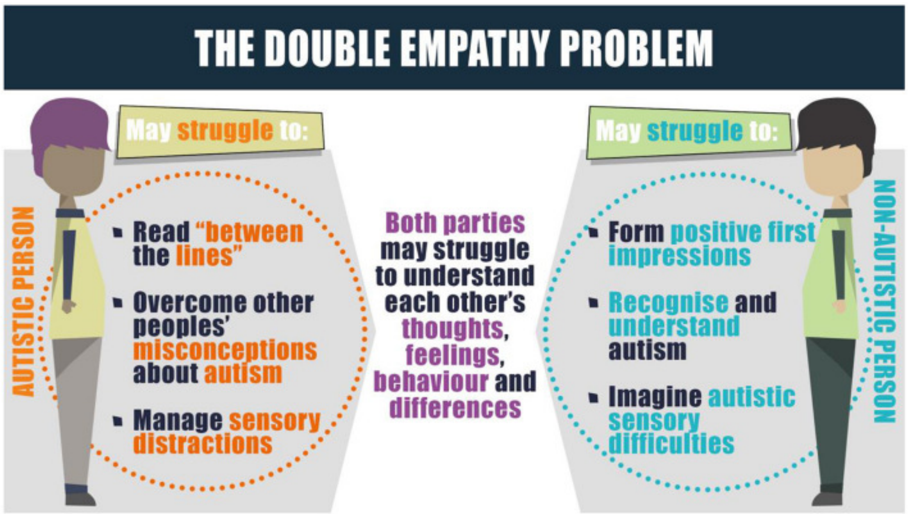

Figure 1

Figure 1

Autistic and non-autistic people can find it difficult to understand each other. The fact that both people in the interaction have trouble with understanding is why the theory is called the double empathy problem.

mismatch between social expectations and experiences can make communication between autistic and non-autistic people difficult. That is why building understanding and empathy is described as a "double problem," because both autistic and non-autistic people struggle to understand each other.

WHAT HAS RESEARCH TOLD US SO FAR?

One way that scientists understand double empathy is to see if people who are not autistic judge autistic and non-autistic people differently. Unfortunately, when people who are not autistic find it hard to understand autistic people, they tend to like them less [2]. In fact, it takes just a few seconds for people who are not autistic to form negative **first impressions** about autistic people [3]. Non-autistic people quickly become less interested in interacting with autistic people than with other non-autistic people, which means that autistic people may have fewer opportunities to meet people and make friends. Why does this happen? It is not because autistic people talk about things that are less interesting. When non-autistic people read the words of what autistic people are saying, they do not judge them any differently than they judge non-autistic people [3]. So, it really seems that it is how autistic people appear and sound, and not what they talk about, that leads non-autistic people to judge and avoid autistic people. Sadly, this means that autistic people might have fewer opportunities to make friends or get jobs because of how non-autistic people judge them, which is not fair.

FIRST IMPRESSION

The mental judgement made when someone encounters another person for the first time. First impressions help a person decide whether they want to be friends with or see that other person again.

Another way to explore double empathy is to see if autistic people connect with other autistic people more easily than they do with people who are not autistic. This is exactly what some new studies are showing. Autistic people want to talk to other autistic people, sit next to them, or live near them even more than they want to do these things with non-autistic people [4]. In one study, two unfamiliar adults got to know each other by talking for 5 min [5]. Sometimes the two adults were both non-autistic, sometimes both autistic, and sometimes one of each. You might expect, if autistic people are poor at social interaction, that the conversations between two autistic people would go especially badly. But that is not what the study found. The quality of interactions between two autistic people was just as strong as between two people who were not autistic. Autistic people even shared more information about themselves with other autistic people, suggesting they felt more comfortable with them. This shows that autistic people are like everyone else: they find it easier to connect with, and maybe even form friendships with, people who think and communicate like they do.

Why might autistic people find it easier to understand other autistic people? Research indicates that autistic people are less likely to rely on typical social expectations for interacting, or be upset if such expectations are not followed [6, 7]. This means that autistic people give each other more freedom to express themselves in unique ways. We can see evidence of this by looking at how well autistic and non-autistic people share information with each other. One recent study was based on the game "Telephone," in which one person whispers a message to another person, who then whispers it to the next person, and so on. The last person then says the message out loud to see how different it is from what the first person said. Researchers compared how accurately groups of autistic people, groups of non-autistic people, and groups with a mix of autistic and non-autistic people shared a story in a game of Telephone [8]. They found that autistic groups share information just as accurately as non-autistic groups. Mixed groups of autistic and non-autistic people were much less accurate. This shows that autistic people are just as able to share information as non-autistic people if they are with other autistic people. This supports the theory of the double empathy problem: that there is a two-way difficulty when autistic and non-autistic people interact.

WHAT DO WE STILL NEED TO LEARN ABOUT THE DOUBLE EMPATHY PROBLEM?

So far, studies of the double empathy problem have focused mainly on teenagers and adults, and it will be important to see if the results differ for younger children. For example, if it turns out that non-autistic children are more positive about autistic people than non-autistic adults are, this would tell us that negative attitudes about autistic people are not destined to happen but are learned over time. Also, because autistic children are more likely now than in the past to be included in classes and activities with non-autistic children, this may provide more opportunities for autistic and non-autistic children to interact and learn about one another. These increased opportunities for interaction might help autistic and non-autistic people to understand each other and decrease the double empathy problem over time.

INTELLECTUAL DISABILITY

A disability characterized by difficulty with learning. A person with an intellectual disability might take longer to learn and may need support when developing new skills, understanding information, and interacting with others.

Additionally, studies so far have only included autistic people who are highly verbal and do not have an **intellectual disability**. According to the theory, the double empathy problem would be even greater between non-autistic people and autistic people who have an intellectual disability, but further research is needed to see if this is the case. Another avenue of research is to explore the effect of familiarity of a relationship. For example, how does the double empathy problem differ when communicating with a stranger vs. a family member? Family members share backgrounds, experiences, and environments, which suggests that the double empathy problem may be reduced within familiar relationships. However, research has shown that familiarity can sometimes create additional barriers. For example, thinking we know someone well might prevent us from listening and understanding what is really being communicated [9].

Finally, although new research suggests that autistic people may communicate more effectively and more comfortably with other autistic people, we do not yet know exactly how or why this occurs. The double empathy theory would suggest that having similar ways of understanding the world helps people understand each other and connect. Understanding whether there are specific ways of communicating that underlie this connection could help us identify ways to bridge the gap in communication between autistic and non-autistic people.

WHY IS THIS RESEARCH IMPORTANT?

Social interactions are a gateway to many things in life—from buying a bus ticket to interviewing for a job. Because most people are not autistic, most social interactions fit the non-autistic communication style but might not work as well for autistic people. Autistic people must navigate many social interactions that are difficult to understand.

By finding out more about how the double empathy problem plays out in real life, we can help non-autistic and autistic people to understand each other better and help them to "meet in the middle." Improving our understanding of the ways that autistic and non-autistic people interact might help autistic people to find it easier to spend time with non-autistic friends and family as well as non-autistic teachers, doctors, and employers. It may help people who are not autistic not to leap to conclusions based on assumptions about autistic people and to be less judgmental of them. This research may also provide people who are not autistic with more creative and accessible ways of communicating with others. Overall, for both people who are autistic and those who are not, understanding how each other communicates can help us build understanding and make the world more inclusive and accepting of everyone—and that is important!

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CONFLICT OF INTEREST: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

YOUNG REVIEWERS

AMELIA, AGE: 15

I am studying for my GCSEs at the local high school in Northumberland, England and I am enjoying all my subjects, both arts and humanities as well as the sciences. I am particularly interested in language and how people think, what makes people different, how different people react in different situations and what are people's motivations for their actions. I also love reading and language–how it changes and evolves. I am currently hoping to study psychology and/or linguistics at university.

ANAND, AGE: 13

An avid learner of science and history, Anand enjoys biology and health science. His specific areas of interest are neuroscience and neurosurgery. Outside of academics, Anand's hobbies includes participating in spelling bees and learning more about roller coasters. He is a black belt in Tang So Do karate.

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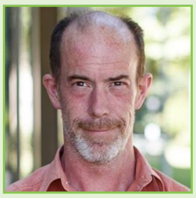
Kilee DeBrabander is a researcher at The University of Texas at Dallas who studies adults with autism and how they are judged based on various characteristics of their personalities and abilities. She also looks at how these judgements may differ depending on if they tell other people about their autism diagnosis, if they are in a social situation or a work/school setting, or if the person making the judgements knows more about what autism is.

BRETT HEASMAN

Brett Heasman is a Senior Lecturer in Psychology at York St John University. He is interested in understanding communication, interaction, and how to remove the barriers that face people who have hidden differences.



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HEALTH
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CAMOUFLAGING IN AUTISM

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YOUNG REVIEWERS:

HANNA AND JULE

AGES: 11–14

Some people with autism try to hide aspects of their autism or develop ways to cope with it. This is known as camouflaging. Camouflaging involves finding ways around things that an autistic person finds difficult, hiding aspects of their autism, and trying to fit in with others. Overall, camouflaging might help some people to make friends, but it can be very exhausting and might even cause people harm.

INTRODUCTION

Do you know anyone who is autistic? The person might be a family member, a friend, someone in school, or even you! **Autism** means that a person can find it hard to interact or communicate with other people, and that he or she might experience the world in a different way. For example, an autistic person might find it difficult to ride on a train, because the noise can seem really loud and scary, but they might also be really interested in learning about animals and love cuddling with their pet. Everyone with autism is different, just like everyone without autism.

AUTISM

A condition in which a person processes the world and understands others differently than most people do. People are born with autism and it affects the way that they grow up. Some autistic people can find it hard to communicate or interact with others, and can feel overwhelmed in noisy, bright, or busy situations.

CAMOUFLAGING

Finding ways to hide autism or make it less visible to other people, even if the autistic person is not aware of doing this.

Some autistic people feel very different from everyone else, and might feel like they have to hide their autism or try to find ways to cope with the things they find difficult. We call this "**camouflaging**," because it is a bit like a chameleon changing the patterns on its skin to fit into the surroundings. The chameleon is still there, but it is trying to look like everything else around it. Examples of camouflaging in autism include forcing yourself to make eye contact with other people even if you do not want to, or thinking of a list of questions to ask every time you meet someone new, so you do not run out of things to say [1, 2].

Everyone—with or without autism—camouflages sometimes. For example, if you are feeling shy about meeting someone new, you might pretend to be really brave even though you do not feel it. But for some autistic people, camouflaging happens every time they talk to someone and this takes a lot of effort [3].

LEARNING MORE ABOUT CAMOUFLAGING

Autistic people have talked about camouflaging for a while [4], but doctors and researchers still do not know very much about it. No one knows whether camouflaging can help people or if it actually causes autistic people more problems. Researchers started to learn more about camouflaging by asking autistic people about their experiences of camouflaging or **masking** their autism [3, 5].

MASKING

Hiding aspects of yourself or pretending to be like someone else. For example, a person might mask their autism by pretending to join in a game even if they do not understand the rules.

Autistic people reported that they camouflage their autism because they want to make friends and form connections with people, and because camouflaging can be helpful to them. Some people might camouflage their autism when they are at school or work, so that people do not treat them differently and they can concentrate on what they have to do. Some people camouflage their autism when they meet new people, so that they can make a good impression and maybe become friends. Some people will stop camouflaging when they get to know someone very well, if they think the person will accept them even when they act more autistic.

COMPENSATION

Finding ways around difficulties associated with autism. For example, an autistic person might compensate for not knowing which facial expressions to make by copying the facial expressions of a character in a TV show.

ASSIMILATION

Fitting in with other people. An autistic person might try to assimilate by always sitting next to the same person in class.

Several studies have found that autistic people use several different strategies to camouflage their autism. You can see a summary of the different types of strategies in Figure 1. For example, some people might practice making friendly faces in the mirror, because they find it hard to make those faces naturally. We call this "**compensation**," because these autistic people are compensating for a difficulty they have compared with non-autistic people. Another strategy is "masking," in which autistic people might hide how they are really feeling by, for instance, copying what someone else is talking about if they do not know what to say. Some autistic people also use strategies to try and fit in with other people, so they are not bullied or treated differently; we call this "**assimilation**." For example, these

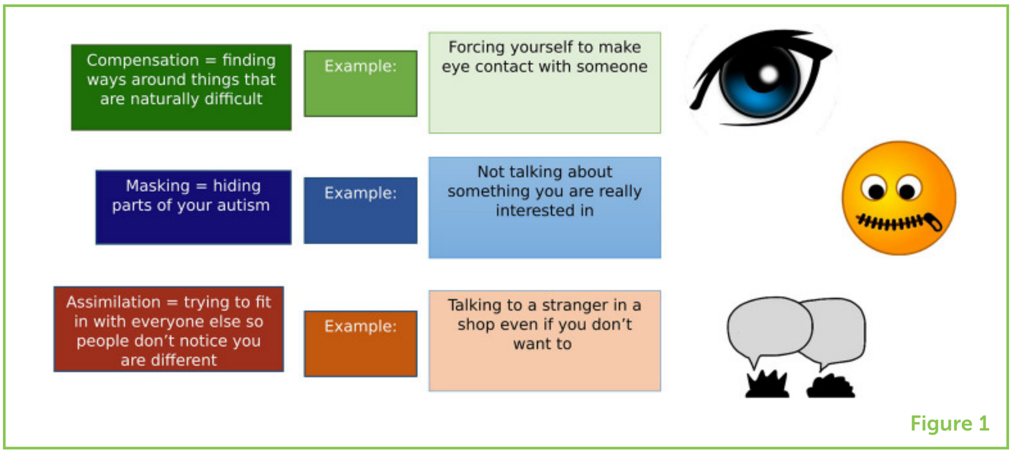

Figure 1

The main types of camouflaging strategies (compensation, masking, and assimilation) and examples of these strategies.

people might stand near other children in the playground, without playing with them.

WHY IS IT IMPORTANT TO UNDERSTAND CAMOUFLAGING?

Autistic people have lots of different feelings about camouflaging. For some people, camouflaging is helpful as it allows them to talk to people, go to school, and get a job without being treated differently because of their autism. But many other autistic people would like to be able to be themselves, and to make friends, without having to hide their autism.

Camouflaging takes a lot of effort. Hiding parts of yourself and pretending to be someone else can be really tiring. Many autistic people say that if they spend a whole day camouflaging at school or work, they need to come home and sit by themselves for a while to recover. One woman in a study said, “It is really exhausting!” [5]. Some autistic people also feel like they are being fake versions of themselves, and they want to be able to stop camouflaging so that their friends can get to know the “real” them.

Researchers can measure camouflaging in different ways. One way is to look at the difference between how someone feels and how they behave. If someone feels like they have a lot of autistic behaviors (such as finding unexpected changes hard to cope with), but other people do not notice this, they might be camouflaging their autism a lot [2]. Another way to measure camouflaging is by asking people how many camouflaging strategies they use, on a questionnaire called the Camouflaging Autistic Traits Questionnaire (CAT-Q [1]).

It is important for researchers and doctors to understand more about how people camouflage, because camouflaging might make people unwell. For example, some studies have found that people who camouflage more also have more mental health problems, such as depression or anxiety. It is important that we learn more about why these mental health problems happen, so we can help people to feel better. There are some situations in which camouflaging might be helpful (for example, in a school assembly where the autistic person has to sit quietly), but there are other situations in which camouflaging might make things harder (such as at a doctor's appointment, when you need to tell the doctor what is wrong). If autistic people can choose when to camouflage their autism, they might be happier and feel more like themselves.

GENDER DIFFERENCES IN CAMOUFLAGING?

Some autistic people and some researchers think that girls camouflage their autism more than boys do. This could be because girls feel more pressure to fit in with other people, or because people often do not realize that girls can have autism. If girls camouflage their autism more often, it could mean that it might be harder for doctors or teachers to realize when a girl is finding things difficult.

There has been a lot of research into gender differences in camouflaging over the last few years, and we still do not have a good answer! Some studies have found that girls show more of a difference between their autistic feelings and their behaviors, which might mean they camouflage more than boys do [2]. Other studies have found that girls and women report using more camouflaging strategies than boys do [1]. However, other studies have found that boys and men also camouflage frequently, which means that doctors and teachers should be aware that autistic boys might also find things hard [3].

We need to do more research in order to fully understand whether gender plays a role in camouflaging autism. At the moment, we know that all autistic people might camouflage their autism, and so it is important that we keep asking all autistic people about how camouflaging affects them.

SUMMARY

In this article, we described what camouflaging is, to help researchers and doctors understand what camouflaging is like for autistic people. Our article also suggests that, although there might be some benefits to camouflaging, such as making friends more easily, it can also be very harmful to autistic people. As many autistic people have said, it is important to make the rest of the world a friendlier place for autistic people, so they can be themselves and still be accepted. Once this happens, there will be no need for an autistic person to camouflage unless he or she wants to.

Now that we know more about what camouflaging is, we want to learn more about how different people camouflage. In particular, are there differences in the ways that boys and girls use camouflaging techniques? Could these differences in how the genders use camouflaging affect whether or not their autism is diagnosed by a doctor? There is still a lot of research to do!

ORIGINAL SOURCE ARTICLE

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., et al. 2017. "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *J. Autism Dev. Disord.* 47:2519–34. doi: 10.1007/s10803-017-3166-5

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YOUNG REVIEWERS

HANNA AND JULE, AGES: 11–14

We are sisters and both of us love to play with our cats. Our favorite subjects in school are art and maths.

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Will Mandy is a research and clinical psychologist. His research covers a wide range of topics, including autism and eating disorders, with recent research focused on helping people get an autism diagnosis, and supporting autistic children as they grow up and change schools.

frontiers FOR YOUNG MINDS

HEALTH
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DEVELOPMENTAL LANGUAGE DISORDER: THE CHILDHOOD CONDITION WE NEED TO START TALKING ABOUT

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YOUNG REVIEWERS:

AMELIE
AGE: 10

ARIELLE AND ELLIOT
AGES: 13 AND 8

Using language is a skill that allows us to share our ideas and feelings, to learn in school, and to understand the world around us. Unfortunately, using and understanding language is not easy for everyone—especially for people with developmental language disorder (or DLD). DLD is a hidden but very common condition affecting about 1 out of 15 children. DLD has been given different names in the past, which has sometimes made it confusing for professionals to talk about the condition and for children with DLD to get help. Researchers have studied the different factors that may contribute to DLD, the different types of language problems children with DLD might have, and how children with DLD can be helped. It is very important that we raise awareness for DLD so that the condition will become less mysterious and the lives of the many children who have DLD will become easier.

LANGUAGE

The use and understanding of spoken words, written words, or sign language to communicate.

Humans use **language** to share ideas and feelings as well as to understand the ideas and feelings of other people. Most of us use language every single day without ever stopping to think about it. Now imagine what it would be like to struggle to understand what people are saying to you or to put your thoughts into words. Think about how hard it would be to share stories, to understand what your teacher is asking you to do, or to explain to your friends why you are feeling upset. This is how it might feel if you had a **developmental language disorder**.

DEVELOPMENTAL LANGUAGE DISORDER

A hidden but common condition that causes difficulty using and/or understanding language.

WHAT IS DEVELOPMENTAL LANGUAGE DISORDER?

Developmental language disorder, or DLD for short, is a hidden but very common condition that means a child has difficulty using and/or understanding language. Children with DLD have language abilities that fall behind those of other children their age, even though they are often just as smart. Having trouble with language means that children with DLD may have difficulty socializing with their classmates, talking about how they feel, and learning in school [1]. DLD is very common. If your class at school was made up of 28 students, there would be about two students in your class with DLD. It is a life-long condition. Even though DLD is usually first discovered and treated in childhood, it usually does not go away as a child grows up. There are many adults with DLD, too [2].

WHY IS IT CALLED DEVELOPMENTAL LANGUAGE DISORDER?

Throughout history, language problems in children have been given many different names. For example, these children have been said to have a "specific language impairment," a "language delay," or a "language disorder," among other labels [3]. Because there were so many different labels being used to describe language problems in children, it was really hard for professionals (like doctors, psychologists, and **speech-language pathologists**) to talk to each other about these problems, because everyone was using different names. The use of multiple terms for the same disorder also meant that it was difficult for researchers to investigate how to help these children. In 2015 and 2016, a group of experts from around the world came together to solve this problem [4, 5].

SPEECH-LANGUAGE PATHOLOGIST

A professional who assesses and treats patients of all ages who have speech, language, communication or swallowing disorders.

The experts agreed that the term "language disorder" should be used to describe severe language problems that will most likely not go away. These language problems make it hard for children to communicate or to succeed in school [5]. Many children have a language disorder along with another disability, like Down syndrome or autism spectrum disorder. Other children, however, could have a language disorder without having any other disability. For these children, the experts agreed that the label "developmental language disorder" should be used [5]. Many people have never heard of DLD, even though it is very common, and that is why it is so important that information about the condition is shared.

WHY DO SOME CHILDREN HAVE DLD?

The answer to this question is very complicated. Although there is a lot of research on DLD, we do not know why some children have it and others do not. DLD is probably the result of a mixture of different factors, including:

1. *Biology*: a child's physical makeup may play a role in whether he or she has DLD. DLD often runs in families, meaning that the genes a child gets from his or her parents may influence whether that child has DLD. The way that a child's brain is made up and how the different parts of the brain talk to each other may also play a role.
2. *Cognition*: every child is different in how he or she learns new information, thinks about that information and uses that information. These processes are called cognition. Some children are fast thinkers, while some are slow. Some children have really good memories, while some do not. These differences in cognition may play a role in whether a child has DLD.
3. *Environment*: the environment that a child grows up in may also play a role in whether that child will have DLD. A child's environment can either increase or decrease the risk of the child having DLD. There are some people who believe that a child will have DLD if his or her parents do not talk to the child enough—this is not true.

There is no recipe of biology, cognition, and environment that guarantees that a child will have DLD or that a child will not have DLD. When a child does have DLD, it is probably the result of different factors interacting with each other [6].

WHAT KINDS OF LANGUAGE PROBLEMS DOES SOMEONE WITH DLD HAVE?

To really understand the kinds of challenges that someone with DLD faces, it is important to know that language is very complex and that there are many different ways that language can be impaired. A child with DLD will have a very unique profile, meaning that he or she will face a unique set of language challenges. This profile may look very different from other children with DLD and the profile may change as the child gets older. Even though every child with DLD is unique, there are some language problems that are very common among children with DLD.

1. *Many children with DLD have trouble using proper grammar*. For example, a child with DLD might say the sentence, "he play outside yesterday," instead of "he played outside yesterday." In this

GRAMMAR

The structure and rules that are followed in a language.

VOCABULARY

The total number of different words that a person knows.

sentence, the child has not added the -*ed* to the end of the word *play* to show that it occurred in the past. A child with DLD might say "I walking to school," instead of "I am walking to school." In this sentence, the child has not included the form of the verb "to be" that fits in this sentence [7]. **Grammar** errors, like these examples, are very common for children with DLD.

2. *Many children with DLD have trouble with sounds.* This type of difficulty is especially common when children are very young. There are many different ways that a child may have trouble with the sounds in words when he or she is speaking. For example, children with DLD might leave sounds out (saying "nana" instead of "banana"). Children with DLD might also use the wrong sounds in certain words (saying "wed" instead of "red").
3. *Many children with DLD know fewer words than other children their age.* The number of words you know is called your **vocabulary**. Problems with vocabulary will look different as a child grows up. Very young children with DLD may say their first words later than other children. It may also take children with DLD longer to learn and remember new words. Even if a child with DLD has learned a word, it may be hard for him or her to remember that word when talking. This problem is called word-finding difficulty. As children with DLD get older, they may not properly learn that some words have more than one meaning (like the word "cold," which can mean a low temperature, a sickness, or being unfriendly [6]).
4. *Many children with DLD have problems properly using language in social situations.* Children with DLD might have trouble staying on topic, taking turns in a conversation, or understanding long sentences. These children may have trouble sharing information and telling stories [8]. It might be hard for children with DLD to use words to talk about how they are feeling. This difficulty with making people understand a problem they are having can make children with DLD feel frustrated or angry, and act in ways they are not supposed to.

Although these language problems are common in children with DLD it is very important to remember that no two children have the same language skills, communication, or learning abilities.

HOW DOES A CHILD WITH DLD GET HELP?

It is very important to know that support from professionals, like speech-language pathologists and teachers, can make a huge difference in the lives of children with DLD. The first step in getting help for a child with DLD happens when someone recognizes that there is a problem. DLD will look different in different children. However, we also know that there are some DLD warning signs that parents and teachers should remember. One DLD warning sign is when a child has problems in school. Language is important for every single subject, so a child with DLD may struggle to understand what he or she is learning, might feel frustrated at school, and might get bad grades. Another DLD warning sign is when a child has language skills that are less advanced than other children the same age. There is a large amount of evidence showing that providing help, also called intervention, for children with DLD can be very effective and can improve that child's language skills. Although many children with DLD will always have language skills that fall behind their peers, getting help can maximize a child's communication and learning potential [1]. By creating greater awareness about DLD, the condition will become less mysterious and children will be helped sooner. We all have a responsibility to share what we know about DLD so that researchers and professionals can continue to work hard every day to help make the lives of children with DLD easier.

ADDENDUM

The article, *Developmental Language Disorder: The Childhood Condition We Need to Start Talking About*, describes the language problems that may be observed in children with Developmental Language Disorder (DLD). The descriptions and examples of language problems in the article primarily focused on standard English. This addendum adds the important point that the common language learning problems observed in DLD will be different for speakers of other languages or other English dialects. An English dialect is a particular form of the English language that a group of people from a specific region or group speak. Some of the common errors that people with DLD make when they are speaking standard English may not be a sign of DLD for someone speaking an English dialect. For example, *he play outside yesterday*, which was given in the original article as an example of a grammatical error in Standard American English, would be a perfectly grammatical production by a speaker of African American English [9]. It is very important for professionals, like speech-language pathologists, to understand the specific dialects that may be spoken in their communities in order to properly identify DLD.

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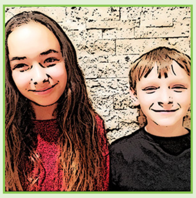
YOUNG REVIEWERS

AMELIE, AGE: 10
I am fascinated about science, in particular about the human body and how it works. Recently I have illustrated a science book for children. I also love traveling and my favorite trips were hiking on the Rila Mountains in Bulgaria and feeding and washing elderly elephants at a rehabilitation center for elephants in Thailand.



ARIELLE AND ELLIOT, AGES: 13 AND 8

Ari and Elliot have been neighbors and friends for the last 7 years. They share a passion for reading and learning. They love to invent their own adventures together with Ari's other sisters. Ari shares her books so much with Elliot that their parents had to put a path through the woods between the two houses. They both love any challenges, which has led to Ari being home schooled.

AUTHORS

ALYSSA KUIACK

I am a Speech-Language Pathology student at the University of Western Ontario completing my Ph.D. I am interested in why some children have trouble learning language and how speech-language pathologists can help. I am also very interested in looking at how teachers and speech-language pathologists can work together, in schools, to help children with their language and literacy development. When I am not doing research, I like to run, read books, and spend time with my family and friends. *akuiack2@uwo.ca

LISA ARCHIBALD

I am an Associate Professor and Researcher at the University of Western Ontario. I am interested in how working memory and language interact in children with communication disorders. Recently, my research has focused on how speech-language pathologists and teachers are able to work together to create language and literacy programs for young learners. I have also been a part of an international team of researchers considering the label and profile of developmental language disorder (DLD).

HEALTH
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STUTTERING AND ITS INVISIBILITY: WHY DOES MY CLASSMATE ONLY STUTTER SOMETIMES?

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[3] *Special Education Department, Barrow Elementary School, Athens, GA, United States*

YOUNG REVIEWERS:

HRISHIKA
AGE: 11

PACHECO ELEMENTARY SCHOOL
AGES: 9-10

PRIYANKA
AGE: 10

When you hear the word "stuttering" what do you think of? Many people think that stuttering is when someone repeats a sound. However, there are different types of stuttering, and each person who stutters has a different and unique way of speaking. Stuttering is like an iceberg because there is a small part of it that we can see (or hear), but a big part of stuttering is invisible. People who stutter have thoughts and feelings about stuttering that we cannot see. Because most people who stutter only stutter sometimes, they must decide if and how to let other people know about their stuttering. We will discuss how stuttering can impact kids and adults and what you can do to support people who stutter.

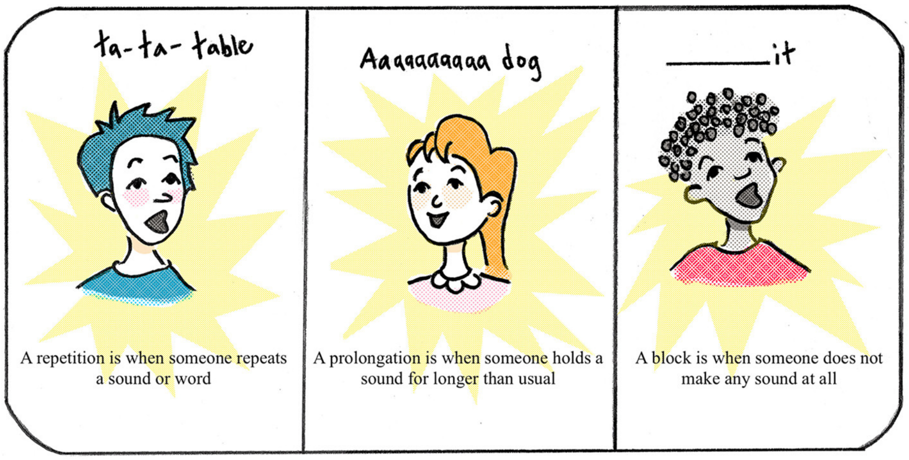

Figure 1

Figure 1

Repetitions, prolongations, and blocks are examples of different types of stuttering-like disfluencies.

WHAT IS STUTTERING?

For many people, talking is something that requires little effort. We rarely think about the complicated ways that the brain, jaw, tongue, lips, lungs, and vocal folds work together to produce speech. How might your life be different if it was difficult for you to say your name? For people who stutter, talking is not always easy. In this article, we will discuss what **stuttering** is and why it is an invisible condition. We will also describe ways to support people who stutter.

STUTTERING

A communication disorder or way of speaking that impacts a person's ability to smoothly link sounds and words together.

Stuttering is a communication disorder that affects the **fluency** of a person's speech, which means the ability to smoothly link sounds and words together. No one has perfectly fluent speech. We all produce **disfluencies** (or breaks in fluent speech) from time to time. For example, it is common to insert words like "um" into speech and to repeat words or phrases on occasion.

FLUENCY

The ability to smoothly link words and sounds together in speech.

DISFLUENCIES

Breaks in fluent speech that are common among all speakers.

Although we all have times when we are disfluent, we do not all stutter. People who stutter produce certain types of disfluencies that are unique to stuttering, called **stuttering-like disfluencies** [1]. For example, people who stutter sometimes repeat sounds or get "stuck" in the middle of a sound. Other times they may have difficulty producing any sound at all. Figure 1 shows examples of different stuttering-like disfluencies.

STUTTERING-LIKE DISFLUENCIES

Disfluencies that are unique to people who stutter, including repetitions, prolongations, and blocks.

One reason why stuttering-like disfluencies are unique is because they are associated with a loss of control. If you have ever slipped on ice, then you have probably experienced a similar feeling. When you feel yourself start to slip, it is normal to tense your muscles or brace yourself for the fall. Some people who stutter react to the loss of control associated with stuttering in the same way. They may tense the muscles of the face, neck, or other body parts. This tension is an example of an associated behavior. **Associated behaviors** are things that people who stutter do when they feel a loss of control during a

ASSOCIATED BEHAVIORS

Things that people who stutter do when they experience the feeling of loss of control while stuttering.

moment of stuttering. Blinking, looking away, and head movements are examples of other associated behaviors.

Stuttering involves more than the behaviors that we see and hear. It also includes thoughts and feelings about communication [2]. Some people who stutter are afraid to talk because of how others may react to their stuttering. Other people who stutter are not bothered by their stuttering, and some people are proud of the way they talk. When it comes to stuttering, thoughts and feelings are important because they influence communication in everyday life, such as if people who stutter are comfortable enough to raise their hands in class or call their friends on the phone.

We have discussed what stuttering is, but what causes stuttering? Stuttering is a result of wiring differences in the brain. There are many factors that influence whether or not a person stutters [3]. One of the primary contributing factors is genetics. Research has shown that there is not just one gene linked with stuttering, but many genes. Around 60% of people who stutter have a family member who stutters [4]. There are 3 million people who stutter in the United States. That is as many people who live in the entire city of Chicago! Boys are three times more likely to stutter than girls, and most people start stuttering when they are preschool age [5].

IN WHAT WAYS IS STUTTERING INVISIBLE?

There are two important reasons why stuttering can be considered an invisible condition. First, stuttering is **variable**. If something is variable, that means that it changes over time. For example, the weather in the state of Michigan during fall is variable because it can be cool in the morning and scorching hot by lunch time. Similarly, stuttering is variable because most people who stutter only stutter sometimes, and the rest of the time their speech can sound smooth or fluent. For people who stutter, this variability can be challenging. They may not know what their speech will sound like from day to day or even from one conversation to the next!

VARIABLE

When something changes over time.

The variability of stuttering can also be confusing for listeners. Just because people who stutter can speak fluently sometimes does not mean that they can speak fluently all the time. If you have a friend who stutters, you may notice that she does not stutter very much in some situations but stutters a lot in other situations. Although it is completely normal, the variability of stuttering can be hard for kids, teachers, and even parents to understand! Regardless of whether we can see or hear a person's stuttering, what they have to say is important and worth listening to.

The second reason why stuttering can be considered an invisible condition is because it is **concealable**, which means that it can be

CONCEALABLE

When something is able to be hidden from others.

Figure 2

Figure 2

Sometimes people who stutter might order something they do not want to eat because it is easier to say. It is important to be patient and give them the time they need to say what they want to say.

hidden from others [6]. Sadness is another example of something that is concealable. Similar to stuttering, we may sometimes feel sad on the inside but try to hide our sadness from other people on the outside. Sometimes people who stutter get a feeling that they are about to stutter on a word right before they say it. Because they sometimes know when they are about to stutter, they may choose to change that word to hide their stuttering. For example, if a person has a feeling that they will stutter on the word "p-p-p-puppy," they may choose to say "dog" instead. Some people are skilled at hiding their stuttering, but it may result in them holding back and not saying what they want to say. Sometimes the consequences of concealing stuttering are even bigger, as illustrated in Figure 2.

WHAT ARE SOME CHALLENGES THAT PEOPLE WHO STUTTER ENCOUNTER?

Because stuttering can be invisible, people who stutter have to make decisions about if and how to let others know about their stuttering. In a survey study, 60% of teenagers who stutter reported that they "rarely" or "never" talk to other people about stuttering [7]. Although some kids prefer not to talk about their stuttering, others prefer to be more open about it. People who stutter can let other people know about their stuttering in different ways. For example, they can say something like, "In case you were wondering, I stutter and that is just the way I talk." They could also choose to let other people see and hear their disfluency by stuttering openly. It should be up to each person who stutters to decide if, when, and how they want to be open about their stuttering.

One reason why some kids may not talk about their stuttering is because they may have been treated badly for stuttering in the past. Most people who stutter have had to deal with **microaggressions** related to stuttering. If we break that word down, "micro" means

MICROAGGRESSION

When someone says or does something that seems harmless, but is actually hurtful toward a specific group of people.

Figure 3

Figure 3

The best thing to do when someone is stuttering is to wait patiently. It can be frustrating for people who stutter when others try to guess what they are trying to say.

small, and "aggression" refers to hurtful attitudes or behaviors. Thus, a microaggression is when someone says or does something that seems small and harmless but is actually hurtful toward a specific group of people. People who commit microaggressions do not always do so on purpose. For example, when people are not familiar with stuttering, they may think it is best to interrupt and guess what people who stutter are trying to say. This experience can be frustrating for people who stutter because they know exactly what they want to say. They sometimes just have trouble saying it. The illustration in Figure 3 provides an example of a microaggression that could happen in real life.

Interruptions are not the only type of microaggression that people who stutter encounter. People who do not understand stuttering sometimes think it is helpful to give people who stutter advice about stuttering. For example, they may tell them to "slow down." Although slowing down can be helpful for some people who stutter, it is not something that all people who stutter like to do. Most people who stutter already have at least some knowledge about what does and does not help their communication.

If people who stutter do want or need additional help related to communication, professionals called speech-language pathologists or even other people who stutter have the appropriate expertise or personal experience to provide support. Some people who stutter may go to speech therapy for help with their stuttering or to improve their overall communication. There are lots of different things that people who stutter might work on in therapy. For example, they may learn about ways to stutter with less tension or work on changing negative thoughts and feelings about communication. Right now, there is no "cure" for stuttering. However, over time, people who stutter can learn and practice ways to make talking easier and more enjoyable.

WHAT ARE SOME WAYS TO SUPPORT PEOPLE WHO STUTTER?

You can support your friend or classmate who stutters by being kind, respectful, and patient. Here are a few other examples of how you can be supportive of people who stutter:

- *Ask your classmate or friend who stutters about specific ways you can support them.* Most kids who stutter probably do not want you to finish their sentences. On a hard speech day, they may be okay with you ordering their school lunch so they can take a break from talking. Sometimes, however, it may be important to them that they order their own lunch. Each situation is different and each person who stutters is different in how they want support.
- *Understand that people who stutter are just like everyone else, but they sometimes need a little extra time to say what they want to say.* Stuttering is only one part of who they are. Build your friendships with them in the same way you would with any other kid based on common interests like sports, art, videogames, or music.
- *Recognize that it is okay to stutter.* Kids who stutter may or may not be in speech therapy, and that is okay. Your friend may be comfortable stuttering in front of you or may choose to use speech strategies when talking with you. Support people who stutter in whatever they choose.

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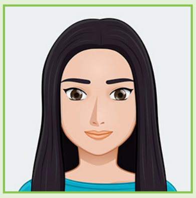
YOUNG REVIEWERS



HRISHIKA, AGE: 11

I am Hrishika and I love animals. I like reading realistic fiction and I want to become a doctor when I grow up.

PACHECO ELEMENTARY SCHOOL, AGES: 9–10

The fourth grade scholars from Pacheco Elementary, a dual immersion school in California, are learning in English and in Spanish. They enjoy learning about the experiences of different kids, listening to funny read aloud books, conducting science experiments, solving riddles, going on field trips, and dancing Zumba.

PRIYANKA, AGE: 10

My name is Priyanka and I enjoy reading, drawing, and imagining creative stories about fantasy and magic. My favorite animals are dragons and snakes and other reptiles. When I grow up I want to become a children's book author and illustrator.

AUTHORS

HOPE GERLACH

I am a researcher at Western Michigan University. I enjoy learning about the day-to-day experiences of people who stutter. I have worked as a speech-language pathologist at several camps for kids who stutter. In my free time, I like to explore the outdoors and spend time with my dog. *hope.gerlach@wmich.edu

ANU SUBRAMANIAN

I am an associate clinical professor at the University of Iowa. I teach graduate students to work with children and adults who stutter. In my free time, I like to read, spend time with my family, and walk with my dogs.

ELIZABETH WISLAR

I am a person who stutters and a teacher of students with disabilities. I live in Georgia with my husband and daughter. I love to run, cook, draw, read, and write. I am a co-leader for the Athens National Stuttering Association Chapter, and I write a blog about being a teacher who stutters.

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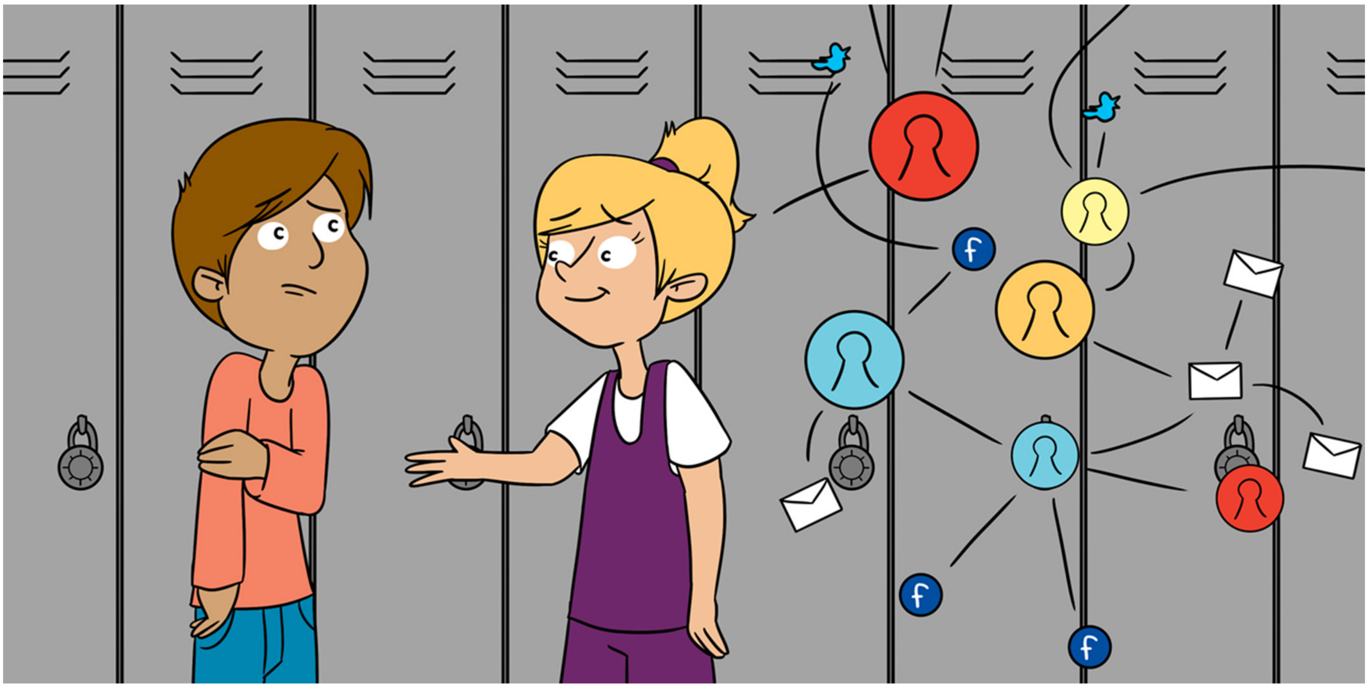

WHY IS IT DIFFICULT FOR YOUNG PEOPLE WITH HIV TO SHARE THEIR DIAGNOSIS?

Michael Evangeli *

Department of Psychology, Royal Holloway University of London, Egham, United Kingdom

YOUNG REVIEWERS:

BROCK
AGE: 13

DRACHMAN MONTESSORI K-8
AGES: 13–14

HIV is a virus that attacks the immune system and weakens a person's ability to fight infections. There are around 37 million people living with HIV, mostly in Africa. Nearly two million people with HIV are under 15 years of age. Most of these children and some older adolescents/young adults were born with HIV. Medication can help people with HIV to lead normal lives, but many young people find it difficult to tell others that they have HIV. Telling others about having HIV can help people get more support, reduce their chances of passing HIV to others, and help them take medication as prescribed. Telling people about having HIV can also feel risky, though, because there is a chance that those people may not react positively. This article presents research focusing on ways to help young people with HIV think about sharing that information, and how we can support children to make the decision to share.

The content of this article is most suitable for young people aged 12 or over.

WHY IT IS DIFFICULT TO TELL SOMEONE A SECRET

Imagine that there was something about you that you wanted to share with a friend. It might be how you feel about your friend or someone else, or something that happened to you that you want your friend's help with. The problem is that you do not know how your friend will react. Will they think differently about you? Will they make fun of you, or tell someone else what you told them? Will they be offended that you had not told them before? You know that you do not have to tell your friend, so maybe it is best just to wait for another time. Or maybe it is best not to tell anyone at all. This is how young people with HIV often feel about telling other people about their HIV.

WHAT IS HIV?

HIV is a virus that attacks the immune system and weakens a person's ability to fight infections and disease. There are around 37 million people in the world living with HIV, mostly in Africa. HIV can be found in bodily fluids which are exchanged when people have sex, in blood, and in breastmilk.

Early signs of HIV infection sometimes include flu-like symptoms, but not everyone will experience symptoms immediately. It may take many years before other symptoms of HIV infection are seen, such as weight loss, recurrent diarrhea, night sweats, skin problems, and infections. HIV cannot be cured, but it is treatable. The treatment involves medicines known as antiretroviral therapy. These medicines control the virus and help people to remain in good health, without anyone being able to tell that they have HIV. If medications are taken as prescribed, people living with HIV can expect to have a normal/near normal life expectancy. That means that they can expect to live for the same length of time as anyone else.

HOW IS HIV TRANSMITTED?

HIV can be transmitted between people in several ways:

- Sex without condoms, with someone who has HIV
- During pregnancy, birth, and breastfeeding
- Sharing infected needles
- Blood transfusions

U=U stands for "Undetectable equals Untransmittable." In other words, when people who are HIV positive are taking their medications properly, the amount of virus in their blood will be so small that it will not be possible to detect it. If this happens, they will **not** be able to transmit the disease to sexual partners.

PERINATALLY ACQUIRED HIV

If HIV is transmitted from mother to child (during pregnancy, birth, or breastfeeding), this is called vertical transmission or perinatally acquired HIV. There are large numbers of young people who have perinatally acquired HIV, including most of the nearly two million HIV-infected children under the age of 15. This group faces many of the same challenges that anyone with HIV faces, including the need to take daily medication for life and go to clinics and hospitals regularly. As they get older, they will need to manage their own health and protect partners from the possibility of HIV transmission. However, people with perinatally acquired HIV have an additional challenge, in that their first sexual relationships will occur when they know that they have a sexually transmittable illness that is often stigmatized. Stigmatized means unfairly thought of by many people as being something to be ashamed of.

SHARING HIV

All people with HIV have to make decisions about sharing their HIV status with others. Telling others about having HIV can lead to more support, less chance of passing HIV to others, and help with taking HIV medications as prescribed. Telling people about HIV can also feel risky, though, because there is a chance that the friend, family member, or partner may not react positively. Negative reactions might happen because some people hold negative views about people with HIV.

As young people with perinatal HIV grow up, sharing their HIV status with partners and others becomes more important, because sharing this information may help them to feel intimacy (emotional closeness) and to gain support. However, in young people with perinatally acquired HIV, rates of sharing an HIV status are low [1]. Sharing is difficult, particularly in relationships, because of a fear of rejection, a lack of confidence about sharing, and concerns that the person being told will tell others [2]. One issue that is specific to young people with perinatal HIV is the attitude of the parents about sharing. Some parents might not want their son or daughter to share this information with others. Also, young people may be concerned that telling others about their own HIV status will reveal the status of their parents, as well.

We have conducted studies exploring the sharing of an HIV status in young people with perinatally acquired HIV. One study focused on intimate relationships in young adults [3]. We found that decisions about starting, continuing, and resuming relationships were shaped by issues around sharing an HIV status. Participants spoke about how fear of sharing affected their relationship decisions:

> *"…maybe that's why I don't think about having a proper relationship, cos it's always in the back of my mind sometimes, I think I'm going to tell a girl the situation, she won't be interested anymore."*

Another study involved interviewing young adults with perinatally acquired HIV who had become mothers [4]. They spoke about feeling socially isolated due to their difficulties sharing their status with others, including their partners:

> *"I would tell them (partners about status) and they would just all of a sudden disappear."*
>
> *"I just thought I would never have kids because of the whole status thing, I just thought that was too much to handle, I would have to tell the person I have this and I didn't think I would find someone that I could openly tell."*

A third study of young adults with perinatally acquired HIV [5] focused on sharing with friends. There was little sharing with friends, because people with HIV imagined that conversations about sharing their status would result in a stigmatizing response from others.

> *"Nowadays you've got Twitter and Facebook and so on. It's like you're connected to so many people…. if you told someone, someone knows someone, who knows someone who… and so, like it's worse to control."*

When people were able to share their status, though, they often found it helpful and it increased their confidence in terms of sharing their status with partners

> *"When [my partner] asked me [why I took medication], I was like ok [I'll tell you], because I'd told (two friends) before, so it wasn't like I was scared"*

One final study [6] focused on HIV communication between mothers living with HIV and their adolescent children with perinatally acquired HIV. It was clear that the adolescents felt that their parents advised them to keep their status secret:

> *"They're completely and utterly against it. Like, they don't want me to disclose because they don't think that like, my friends will stay…that if things go badly that at the end of the day, you just lost a friend and like, the implications that it can have on your life like, you don't know who that person is going to tell."*

HELPING YOUNG PEOPLE TO SHARE THEIR HIV STATUS

Young people with HIV, and professionals working with them, say that they would like more guidance about sharing an HIV-positive status. Researchers and healthcare professionals in the UK and Uganda are, therefore, trying to develop a four-session programme to help young people with perinatally acquired HIV to make decisions about sharing their status. This will be for adults between 18 and 25 years of age. The programme will include three group sessions for both males and females (run by a professional and a peer worker), to help young people explore their motivation to share their HIV status and build sharing skills. Then there will be one individual session to work on developing a sharing plan. We will develop the details of the programme by interviewing young people with HIV, their friends, family, and partners, and health care professionals. Then we will compare the programme with the usual care given in the UK and Uganda, to see whether it is reasonable and acceptable. Typical HIV care in both countries does not involve any routine or structured programmes to help young people to share their status. We hope that this programme will eventually become an approach that young people with HIV can use to help them with decisions about sharing their status no matter where they are in the world.

FURTHER READING

The Children's HIV Association have a great website where you can find out more about children and young people living with HIV—https://www.chiva.org.uk/.

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YOUNG REVIEWERS

BROCK, AGE: 13
My interests include baseball, football, fishing, the outdoors, and reading. For the future, I am interested in becoming a conservationist or a scientist. I am particularly interested in trout and their habitats and the whirling disease that has impacted our Canadian lakes and rivers. I am an avid fisherman and am currently learning how to fly fish. I love science and I am very curious about the world around me.

DRACHMAN MONTESSORI K-8, AGES: 13–14
We are 15 eighth grade borderland kids at a public Montessori K-8 in Baja Arizona… and we have been working together so long, we are one big crazy family, like siblings, that lowkey like each other. We enjoy chillin', playing sports, and making each other laugh. Even our flatheads are actually smart. We are young but together we are strong.

AUTHOR

MICHAEL EVANGELI
Dr. Michael Evangeli is a Reader in Clinical Psychology with research and clinical HIV experience in the UK and Africa. In addition to his doctoral clinical training, he has a Public Health in Developing Countries M.Sc. He has led or is leading on studies evaluating psychosocial interventions for young people with HIV in the UK, Uganda, and Botswana. His main research interests relate to psychological

and behavioral aspects of HIV. There are five main inter-related themes to this work: HIV testing; HIV-related behavior change; Psychological elements to individuals’ engagement with HIV care; Well-being and adjustment in HIV; HIV sharing/communication. *michael.evangeli@rhul.ac.uk.

HEALTH
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CHRONIC PAIN: A POORLY UNDERSTOOD EXPERIENCE IN YOUNG PEOPLE

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[2] *Faculty of Natural Sciences, University of Stirling, Stirling, United Kingdom*

YOUNG REVIEWERS:


ANNA
AGE: 11


CHARLOTTE
AGE: 15


INCA
AGE: 10


JAZMIN
AGE: 15


OWEN
AGE: 8


PRAJEETH
AGE: 12

Pain is a common experience in everyday life and part of our earliest experiences as babies and toddlers. Most pain that we experience does not last very long and is "helpful," as it teaches us how to avoid situations that can cause us harm. However, not all pain is short term or helpful. Pain that is continuous or comes and goes for a minimum of 3 months is called chronic pain. Chronic pain is common in children and teenagers and can affect many areas of young people's lives, such as sport, school, sleep, mental health, and friendships. Unfortunately, we do not understand this experience of chronic pain in young people, and how it affects their lives, very well at all. It is really important that we develop a better understanding of how we can support young people with chronic pain and their families to live full lives.

WHAT IS PAIN AND HOW DO WE DESCRIBE IT?

Asking a question like, "What is pain?" might seem silly. Surely everyone knows what pain is, do not they? You accidentally brush your hand on a hot stove or bang your elbow on a table and suddenly it hurts. Pain is a common part of everyday life and it helps us to learn to avoid situations that might cause us harm. Once you know that touching a hot stove is painful, you try to avoid doing it again.

Pain is also a big part of our earliest life experiences. Toddlers fall down and bump into things as they learn to walk and babies cry at the sudden pain of a routine injection. In a recent study, researchers observed children aged 1–2 years in a play centre and reported at least one painful event (such as a fall or a bump) per hour per child [1]. Luckily, these types of painful experiences usually last only for a short time and then go away. This type of pain is called **acute pain**.

ACUTE PAIN

Pain that lasts <3 months.

Pain is not always short lived, however. You may well be able to think about times where pain has lasted for a really long time, even if it is not present all the time. Examples can include experiencing regular headaches or breaking an arm over a year ago, but still experiencing pain in this arm and not being able to use the arm properly. This is an example of pain that is not helpful as it is not providing any useful function, such as preventing use of an injured arm. Pain that is continuous, or comes and goes for at least 3 months, is called **chronic pain**. Unfortunately, we do not understand the experience of chronic pain very well.

CHRONIC PAIN

Pain that lasts for 3 months or longer.

To try and better understand the experience of chronic pain, various measures have been developed to measure the severity of the pain experience. There are numerous ways in which pain can be measured, from observing pain behaviours, such as grimaces in babies, to asking young people to rate their pain on a scale of 0 (no pain) to 10 (worst pain imaginable). Measures like these are called numerical rating scales and focus on assessing the "severity" of pain.

HOW COMMON IS CHRONIC PAIN IN YOUNG PEOPLE?

We know that chronic pain is commonly experienced by children and teenagers (we will use the term "young people" to refer to the combined group of children and teenagers throughout the article). A recent study conducted across 42 different countries found that 44.2% of young people reported experiencing weekly pain over the past 6 months, with rates differing between countries [2]. Remember that this number says nothing about the impact of this pain on the lives of these young people, with many young people likely living a full life. An older study of young people with chronic pain highlighted that about 5.1% of young people with chronic pain had pain so severe that it impacted their daily lives, stopping them from doing things that they wanted to do [3].

The research data tell us that chronic pain is more common in girls and that the experience of chronic pain increases as children become teens. We do not know why pain increases during puberty or why it is more common in girls, although higher levels of chronic pain have also been found in women compared with men.

ARTHRITIS

A health condition that causes swelling, stiffness, and pain in a person's joints.

Chronic pain can be part of an ongoing health condition in young people, such as **arthritis**, inflammatory bowel disease, or chronic fatigue syndrome, or it can occur for no obvious reason at all. Research is beginning to look at why some young people develop chronic pain. For example, one current study is looking at why some young people still experience pain even once a fractured bone has healed. You can read more about this study here.

HOW CAN LIVING WITH CHRONIC PAIN AFFECT YOUNG PEOPLE'S LIVES?

There are lots of different ways that living with chronic pain can affect young people's lives (Figure 1). We know that it can make it difficult for young people to sleep, take part in sports, concentrate, attend school and go out with friends or family. With this in mind, it is not surprising that one of the biggest challenges that young people who live with chronic pain face is poor mental health. In fact, young people report high levels of anxiety and depression, with some mental health problems remaining as the young person becomes an adult [4].

Chronic pain also often disrupts young people's school life. We know that living with chronic pain can make attending school difficult, with young people missing many school days. One US based study found that young people with chronic pain that is not related to a medical condition missed almost nine school days over 3 months, resulting in greater absences than young people with arthritis and pain free young people [5]. In some extreme cases, studies have shown that young people who are very disabled by their ongoing pain may have to repeat a year. Even if these young people can attend school, experiencing constant pain can make it difficult to concentrate and take part in activities. Missing out on school activities can disrupt learning and also make it difficult to make new friends or keep up with existing friends.

PERSONAL IDENTITY

A sense of who you are as a person and what makes you unique.

Living with chronic pain can also affect young people's sense of who they are and what makes them unique. We call this process forming **personal identity**. Forming personal identity is tricky for any young person, but can be particularly challenging for young people who need to find a sense of who they are despite living with chronic pain [6]. For some young people, their pain becomes part of their sense of who they are, so they see themselves as teenagers who live with chronic pain. Other young people are keen to think about their pain as separate from their sense of who they are. So, they see themselves as people who love dancing and chatting with friends but who just happen to live with chronic pain.

Figure 1

Figure 1

Some of the ways that chronic pain can impact various aspects of young people's lives.

The impact of chronic pain can extend beyond the young person and affect their parents and caregivers. In particular, we know that parents of young people who live with ongoing pain often report feeling anxious and depressed. Studies have also shown that parents of young people who are extremely disabled by their pain report challenges with managing a full social and work life. This impact on parents' lives is often because their child with pain is heavily dependent on them, much more so than young people of a similar age who do not experience pain [7].

HOW DO OTHERS MAKE SENSE OF PAIN THAT IS HARD TO SEE?

One of the biggest problems faced by young people with chronic pain is that pain is often invisible to others. If you break your leg, you might have your leg in a cast. This cast makes it easy for people to see your pain, and it is a clear sign to be careful around your leg. It also lets other people know to be patient with you, since you would not be up and running around for the next few weeks. But what happens when pain is ongoing and there is no obvious cause or no visible sign, maybe "just" a painful back that is better some days than others? So, one day you can make it into school, but the next day you cannot, because it is too painful to get out of bed. Friends, family, and teachers might find it really tricky to understand how you can experience ongoing pain when they cannot see what is causing the pain or how pain levels can change very quickly from day to day. Friends might find it difficult to understand why you sometimes need to cancel plans at the last minute when you feel poorly. If this happens frequently, your friends could think that you do not want to hang out with them anymore, and no longer invite you to meet up. Issues like this make it harder for young people with chronic pain to maintain friendships. Scientists do not know much about the long-term effects that tricky friendships in the teen years can have on young people with chronic pain as they get older.

WHAT TREATMENTS ARE AVAILABLE FOR YOUNG PEOPLE WHO EXPERIENCE CHRONIC PAIN?

You might think that drugs are the obvious choice for managing chronic pain in young people, but in actual fact, we do not know a lot about whether drugs, and which drugs, help reduce chronic pain in young people. That is not to say that drugs do not work or that doctors do not use them in these cases, but simply that not enough good quality studies have looked at this issue. So, what do we know?

We do know that psychological techniques, such as setting achievable goals and relaxation, can be useful for helping young people with chronic pain to get back to doing the things they want to do, like going out with friends, going to school, or playing sports. These psychological treatments might include things like **cognitive behavioural therapy (CBT)**, which aims to change how young people think and feel about their pain and how they (and others, like parents and teachers) respond when they experience pain. Figure 2 shows how CBT treatment addresses thoughts, feelings, and behaviours about a particular phenomenon—in this case, chronic pain.

COGNITIVE BEHAVIOUR THERAPY (CBT)

A psychological therapy that involves changing the way that people think and behave about pain.

For example, lots of young people are understandably worried about the possible damage that moving a painful area might cause to their body. Not moving painful areas over time can lead to loss of muscle strength and fitness. To help young people engage in gentle

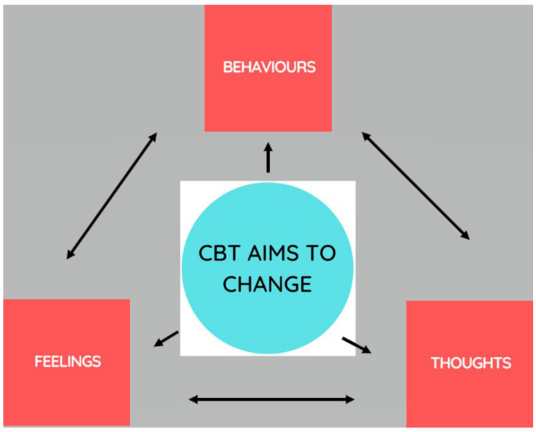

Figure 2

Figure 2

Cognitive behavioural therapy can be used to treat chronic pain. In CBT, treatment addresses thoughts, feelings, and behaviours about a particular phenomenon—in this case, chronic pain.

movement of painful areas, CBT challenges their thoughts and feelings about what will happen if they try move the painful area. CBT does not usually focus on reducing the pain itself, but instead focuses on reducing the disruptive impact pain has on the young person's life. There is good evidence available that CBT helps young people to get back to doing the activities that are important to them [8].

ACCEPTANCE AND COMMITMENT THERAPY (ACT)

A psychological therapy that focuses on accepting pain and giving up the struggle to change thoughts and feelings about pain.

A newer therapy for treating chronic pain in young people is called **acceptance and commitment therapy (ACT)**. Although it has some similarities with CBT, ACT focuses on helping young people to accept their pain and to stop struggling over changing difficult thoughts and behaviours related to pain. ACT encourages young people to focus on the present, through activities, such as mindfulness exercises and allowing thoughts to occur in a way that is not overwhelming. ACT hopes to achieve the same goal as CBT: to help young people begin to take part in activities that they value, like going out with friends. However, not many studies have used ACT to treat chronic pain in young people, so there is not yet much evidence to tell us whether ACT is effective in supporting young people to manage their pain and its effects.

Neither CBT nor ACT focus on reducing the pain itself. Instead, they focus on reducing the disruptive impact pain has on the young person's life, by supporting young people (and their parents) to address things that the young people can change and that are important to them. These treatments often involve working to improve sleep, mood, and exercise or movement. Young people and their parents can take part in CBT and ACT either individually or with a group, and either face-to-face or online. Young people tend to enjoy a group approach, as this means they get to meet other young people who truly understand what it is like to live with chronic pain. Interestingly, some CBT and ACT treatment programmes for chronic pain in young people are also beginning to include parents as well as young people.

CONCLUSION

We hope that we have shown you that chronic pain is a common experience for children and teenagers and that, for a smaller group of young people, it has a huge impact on many areas of their lives and the lives of their parents and families. The experience of chronic pain is complicated, because everyone experiences pain differently. Additionally, the fact that chronic pain itself is often invisible makes it difficult for others to understand, but also difficult for young people themselves to make sense of the pain. While some help is available for young who experience chronic pain, more research is needed to understand which treatments work best for which young people and their families. To address the issue of the invisibility of pain, it is very important to increase public awareness of how chronic pain can affect young people and what can be done to support them.

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YOUNG REVIEWERS

ANNA, AGE: 11
My name is Anna. I love math and science. My favorite thing to do is read. My favorite sport is taekwondo. My favorite food is sushi. If I were an animal, I would be a cat. I want to live by the quote, "I do not regret the things I have done. I regret the things I did not do when I had the chance."

CHARLOTTE, AGE: 15
I am a 15 years old who loves to play games! I can play piano to some extent and clarinet, and I love to eat fruit!

INCA, AGE: 10
Inca is a 10-years-old sixth grader who loves Science. Her hero is Rosalind Franklin who discovered the DNA double-helix. Inca's favorite subjects are Science and Mathematics in school. Inca is an avid reader and a writer. She is also passionate about music and drama. When off stage she enjoys playing chess, swimming, and hiking. Inca is an enthusiastic backpacker with her mother and has climbed four volcanoes. Favorite Quote: Be less curious about people and more curious about ideas—Marie Curie.

JAZMIN, AGE: 15
Hello, my name is Jazmin. My interests include STEM, particularly science. I also enjoy reading books, being a competitive swimmer, being an environmentalist, and volunteer work.

OWEN, AGE: 8

Owen is eight, and enjoys baseball, wallball, reading books, and playing card and board games with his family and friends.

PRAJEETH, AGE: 12

My name is Prajeeth, but I go by PJ. I go to Newark Junior High School, and am in eighth grade. I love playing soccer and reading books, and am glad to have this amazing opportunity!

AUTHORS

ABBIE JORDAN

I am a psychologist at the University of Bath and a member of the Bath Centre for Pain Research, an International Centre of Excellence for Pain Research. Within the Centre, I lead the Child and Family research theme. I am interested in how living with chronic pain affects young people and their families and how children, teenagers, and family members make sense of pain. Another focus of my work is studying how chronic pain affects developmental processes as children become teenagers and then young adults. *a.l.jordan@bath.ac.uk

LINE CAES

I am a psychologist at the University of Stirling, Scotland, with a passion to understand how young people and their parents interact with each other when the young person is in pain. I explore how these interactions change across a child's development, from when the child is a toddler to when they become a young adult. In another part of my research, I also look at how we can improve psychological treatment for young people with chronic pain and their parents.

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HITTING YOUR HEAD CAN RESULT IN INVISIBLE DISABILITY THAT AFFECTS YOUR BODY AND BEYOND!

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YOUNG REVIEWERS:

BIHAN
AGE: 14

DIBA
AGE: 13

Traumatic brain injury (TBI) can occur when someone hits his, her, or their head or experiences another type of trauma to the brain. TBI can have lasting effects on the body, emotions, and more! TBI is common, yet people often do not understand how serious it can be. A good understanding of TBI and its effects is important so that doctors and nurse practitioners can diagnose and treat TBI correctly. People who suffer these injuries may experience mood swings, trouble focusing, or other changes from the way they used to be. Since it may not be easy to tell at first that these problems are related to TBI, we often refer to the long-term consequences of TBI as invisible disabilities. In this article, we will talk about the causes of TBI, the invisible disabilities people experience after a TBI, and how healthcare providers are trying to promote recovery.

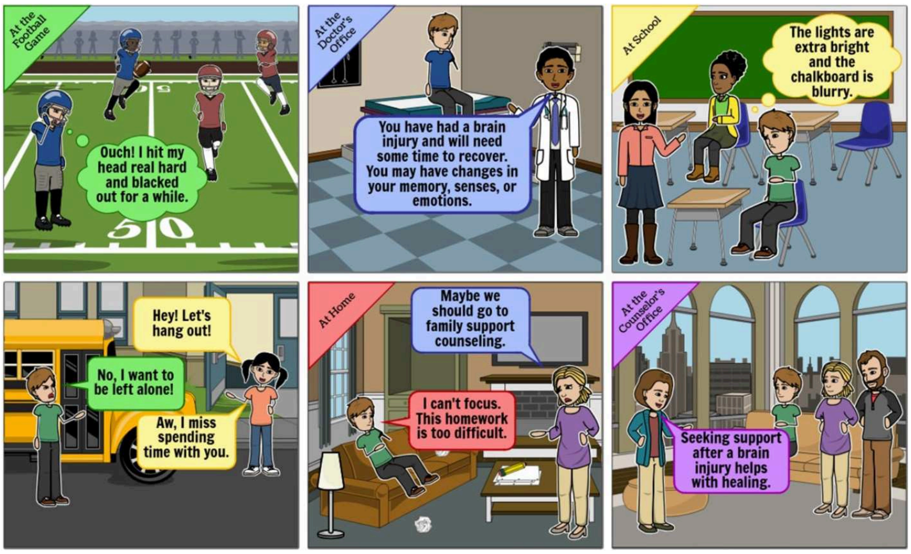


Figure 1

Living with an invisible disability after a TBI can affect a person's everyday activities. TBIs can cause physical, emotional, and learning-related changes. It is important for TBI survivors to seek out support for their invisible disabilities.

TBI AND INVISIBLE DISABILITIES

Traumatic brain injury (TBI) is most commonly caused by a hit to the head due to being tackled while playing sports, being involved in a car accident, or getting hit with a hard object. TBIs can range from mild to severe, with some people quickly returning to school sports and others suffering permanent brain damage. The consequences of TBIs are considered an **invisible disability**, because they can occur in daily life, but the person does not outwardly appear to have a problem, since there is no need for a wheelchair, walker, or crutches. For example, someone who is recovering from a TBI may be dealing with subtle changes in mood, vision, and sensations in the legs.

TRAUMATIC BRAIN INJURY

Brain damage as a result of a violent hit or jolt to the head.

INVISIBLE DISABILITY

A physical, mental, or neurological condition that is not visible to others. Examples are traumatic brain injury, depression, and anxiety.

Since many TBI symptoms are not obvious, this can cause others to underestimate how severe TBI can be. People may think that someone who is blaming bad grades on an injury that occurred months ago is exaggerating. Another misconception is that people can recover from TBIs more quickly if they work harder in school or at physical therapy. This is not true, and if the TBI symptoms are serious enough, participating in therapy may be challenging [1]. Invisible disabilities are diverse, as shown in Figure 1, and can result in a variety of physical, emotional, and learning or memory-related challenges that are just as important, if not even more so, than any visible disability from a TBI.

Fortunately, research advances have led to a better understanding of the various TBI symptoms. There are several research methods that scientists use to study TBI. For example, some scientists ask patients to describe their experiences in their own words, via interview. Other researchers use surveys or laboratory tests. Data can be collected at a single time point, or at multiple timepoints after injury. In many studies, including the one we will describe, patients are studied for long periods of time after they are hurt, so that researchers can see what will happen to them over the course of recovery. Additionally, experiments are often run on patient samples (like blood and saliva) to measure levels of certain proteins. The amounts of different proteins in a sample can determine how serious or mild the TBI is and these levels may be useful for tracking recovery as time goes on. With the knowledge gained from these studies, researchers hope to better educate the public about TBIs and work toward improving current treatments.

PRIMARY AND SECONDARY INJURIES

TBIs have two phases. The initial injury to the head is called the primary injury and could be a bruise on the brain or a fracture to the skull. The severity of the primary injury can determine how long it will take the person to recover and whether or not a full recovery is likely [1]. After the primary injury, the brain often suffers **secondary injuries**, such as **oxidative stress**, inflammation, **excitotoxicity**, and **hypoxia** [2]. Oxidative stress occurs when certain molecules in the brain get out of balance, and this can cause permanent damage to the neurons, which are the cells that send information about the outside world to the brain [2]. Inflammation is swelling in the brain, often due to high levels of certain proteins, and it can result in even more tissue damage than the primary injury [3]. In excitotoxicity, brain and nerve cells become overly excited. Because cells need to rest just like we do, excitotoxicity can prevent cells from functioning at their best [2]. Lastly, hypoxia is when very little oxygen flows into the brain, which is a problem because oxygen is needed to feed the brain and keep it working properly. The main reason we care about these secondary injuries is that they likely contribute to long-term invisible disabilities. Since these secondary injuries often last for a while after the primary injury, treatment of the secondary injuries might be necessary. For example, if a person's brain has too much inflammation, perhaps anti-inflammatory drugs like aspirin would be useful.

SECONDARY INJURY

Indirect injury resulting from processes initiated by the primary injury.

OXIDATIVE STRESS

Secondary brain injury; caused by too many of some molecules and too few of others.

EXCITOTOXICITY

Secondary injury in which brain and nerve cells become too excited, preventing them from functioning properly.

HYPOXIA

Secondary brain injury in which the brain does not receive enough oxygen.

LONG-TERM EFFECTS OF TBI

Every TBI is different, leading to a wide variation in invisible disabilities. Since the brain controls everything, TBI can cause many changes in a person's movement senses, emotions, and memory. Sometimes these changes last a few months after the TBI, but other times they are permanent! The most common types of disabilities that follow TBI and their treatments are summarized in Table 1.

Physical Challenges

After TBI, physical changes involving movement and the functioning of the senses can occur. TBI survivors may have slower movements, difficulty picking up objects, weakness in the arms or legs, or

Table 1

Possible disabilities caused by a TBI treatment strategies [4].

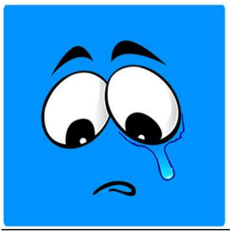
Category	Invisible disabilities that may occur after TBI	Treatment strategies
Memory and Learning 	- Trouble solving problems - Memory loss - Difficulty communicating - Lack of attention	- Stay mentally active by doing crossword puzzles, reading, etc. - Make a to-do list or use a planner - Get enough rest - Eat healthy foods - Exercise
Vision 	- Double vision - Blurry vision - Light sensitivity - Lack of depth perception - Poor peripheral vision	- Visit the eye doctor regularly - Wear eyeglasses or contact lenses when needed - Wear sunglasses - Use a bigger font size on computers and phones
Taste and Smell 	- Changes in taste - Inability to smell	- Eat a wide variety of food - Use more spices to activate taste buds - Practice mindful eating, experiencing food with all senses - Regularly brush and floss teeth
Emotions 	- Emotions going up and down - Lack of energy - Loss of interest in activities - Wanting to be alone more - Sleeping more hungry less often	- Talk to a doctor or counselor - Make time for social interaction with friends and loved ones
Temperament 	- Temper tantrums - Impulsive behaviors - Frustration - Fear and anxiety over little things	- Use meditation and relaxation exercises - Practice deep breathing - Listen to music - Talk to a counselor

Table 1

clumsiness and lack of coordination. While these symptoms may be visible to others if they are severe, milder problems may be an invisible disability [4]. Physical therapy and exercise can help a TBI patient to regain strength and coordination. Other physical changes that are typically not noticeable to others include changes in smell, taste, touch, hearing, or vision [4]! Sensory changes can affect everyday life. For example, a person's favorite food may taste bland. The sense of smell can be crucial; for example, if someone is having trouble smelling and he, she, or they walk away from the kitchen while cooking, it may not be possible to smell the smoke if something was burning! Vision changes, like blurry vision or seeing double, can also occur [4]. If this happens, glasses or contact lenses might be needed.

Emotional Challenges

Emotional changes of various types can occur after TBI. These changes can be so small that they are hardly noticeable or so obvious that the person seems totally different than before the TBI. Common emotional challenges after a TBI include lack of motivation, feeling sad more often, feeling anxious, wanting to spend time alone, feeling sleepier, being less excited about participating in favorite hobbies, and more [4]. A person's emotions help make them who they are, so these emotional changes following TBI can be difficult for both the person with the invisible disability and their loved ones. Therefore, it is important to be patient and kind with someone recovering from a TBI. They are not trying to act in a different way on purpose.

Learning and Memory Challenges

Learning ability, knowledge, memory, attention, problem solving, organization, and communication can all be impacted by TBI [4]. Trouble focusing on homework and lack of motivation to complete assignments could be a sign of an invisible disability. After a TBI, it can be harder to remember things like people's names or where objects were placed. Ways to combat these memory changes include studying with flashcards, making to-do lists, and using smartphone apps.

TREATMENT PROGRAMS AND SUPPORT SERVICES

People who experience an invisible disability after a TBI have unique needs. Current therapies for people with visible disabilities, such as muscular dystrophy or blindness, do not always help people recovering from TBI. Data shows that people recovering from TBI prefer to focus on regaining important skills so that they can resume the lifestyle they had before the injury [5]. The top needs expressed by TBI survivors are improving memory, enhancing problem solving, receiving education, developing job skills, and managing emotions [5]. TBI survivors often do not get help with taking care of themselves and loved ones, or with earning and managing money [5]. Other important needs of TBI survivors include restoring memory and emotional control [5]. As shown in Figure 2 below, certain things are important for the recovery from TBI, including spending time with loved ones, doing things that are enjoyable and bring happiness, talking to a doctor about what is going on, and attending support groups for people who are living with invisible disabilities. It is just as important to address any invisible disabilities as it is to address visible disabilities because sensory, emotional, and cognitive health affect daily life.

It is also important to make sure that there is support for family and friends who may be affected by changes in their loved one after a

Figure 2

Figure 2

Four real-life examples of the various ways TBI survivors can receive support for invisible disabilities. Clockwise from the top left, these methods include spending quality time with family and friends, being physically active, such as hiking with friends, talking to a doctor or therapist, and attending a support group for people with similar experiences. Reproduced from Clipart Library [6].

TBI, such as changes in communication, affection, and behavior [4]. Right now, the majority of help available for family and friends of TBI survivors is through hospitals, medical centers, clinics, or hotlines. Keep in mind that recovery also takes a while for the family and friends. It may be helpful for TBI survivors and the people closest to them to try to get involved in, or start, a support group for those going through similar situations. Support groups can share coping strategies and relaxation tips to use when TBI survivors are going through a tough time.

CONCLUSION

TBIs can have many different causes and can result in a variety of effects and secondary injuries, resulting in changes in learning, memory, senses, emotions, and beyond! These secondary injuries result from brain cell or tissue damage that occurs following the primary injury. It is important to understand TBI and its possible effects on both the patient and the people they interact with. Receiving treatment when an injury first occurs, and throughout the recovery period, will help improve the outcome of a TBI [4]. Seeking support from family, friends, or health professionals is especially important when dealing with TBIs. TBIs can be scary and challenging, but with the right knowledge and tools, patients can be prepared to overcome TBI and its obstacles, both immediately and in the future. Hopefully, this article has shed light on the invisible disabilities that people face after

TBI, so that we can be more aware of the risks of invisible disabilities. By being more patient and understanding with ourselves or loved ones after TBI, we can best help to promote recovery.

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YOUNG REVIEWERS

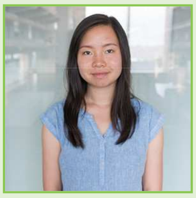
BIHAN, AGE: 14

I am a junior school student. I started learning biology from grade one and I find it is interesting to learn about the creatures on earth. I like the extracurricular activities of biology. The secrets of the human body fascinate me a lot. I love exploring the behavior of human beings.

DIBA, AGE: 13

I do a lot of dancing and horse riding, but when I am tired I like reading books or watch documentaries. I like asking questions a lot.

AUTHORS



JANET LE

I am an undergraduate student at the University of Texas at Austin and I am pursuing a Bachelor of Science in Human Biology, as well as minors in History and Ethics and Leadership in Healthcare. After I graduate, I hope to attend medical school and become a doctor. In my spare time, I like to ski (while wearing a helmet, of course), try new restaurants, and watch movies. lejanet123@gmail.com

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I am graduate of Texas Tech University with a Bachelor of Science in Kinesiology and a Bachelor of Arts in General Studies with concentrations in Biology, Psychology, and Sociology. Currently, I am working in the medical field, with hopes of attending graduate school to become a Physician's Assistant specializing in Internal Medicine. In my free time, I enjoy spending time with my two dogs, traveling, and running. saraemmorgan@gmail.com

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NICOLE OSIER

I am a principal investigator at University of Texas at Austin. I have bachelor's degrees in Nutritional Science and Nursing from Michigan State University, and a PhD from the University of Pittsburgh. My goal is to better understand what makes some individuals recover better than others after head injury. My ultimate goal is to apply new knowledge to help doctors and nurses treat people with head injury, so patients recover as well as possible. To learn more about my laboratory, visit my publicly available website: `https://nicoleosier.wixsite.com/osierlaboratory/` or follow @osierlaboratory on facebook, twitter, or instagram. In my free time, I enjoy spending time with my spouse and cats and traveling the world. *nicoleosier@utexas.edu

HEALTH
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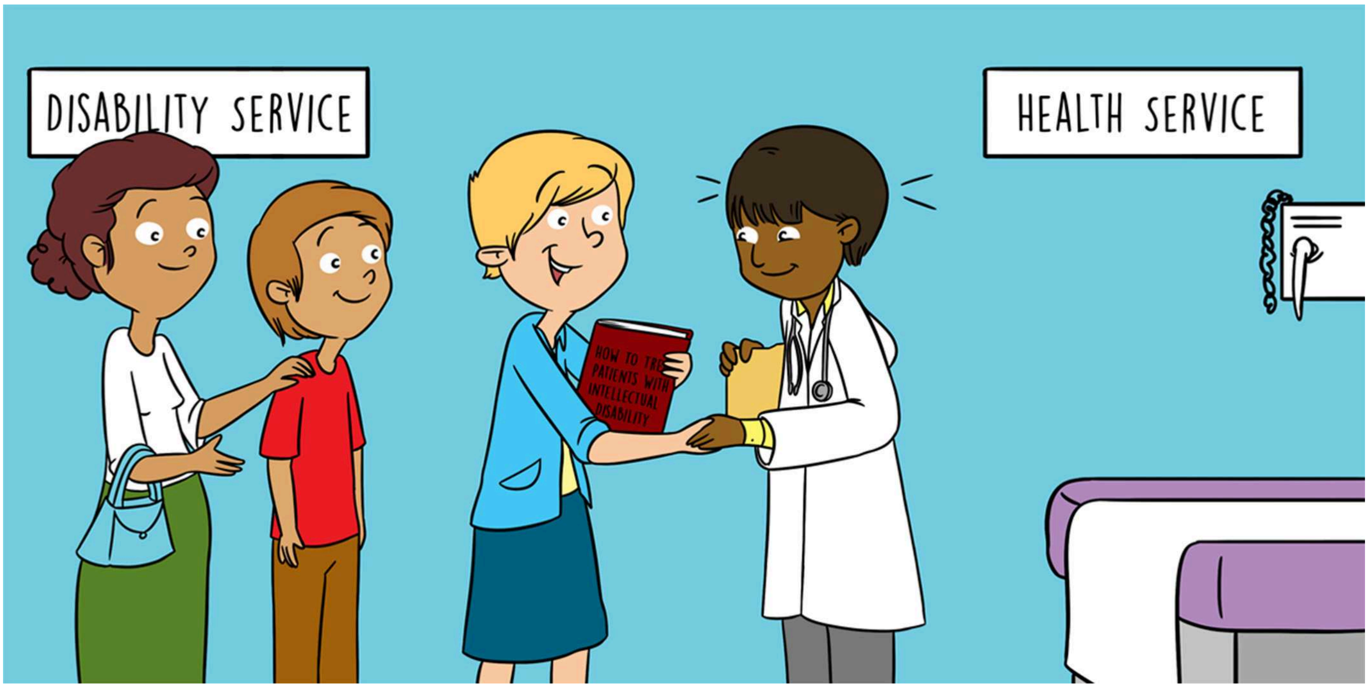

HOW CAN WE PROVIDE BETTER HEALTHCARE FOR PEOPLE WITH AN INTELLECTUAL DISABILITY?

Simone Reppermund*, Janelle Weise, Rachael Cvejic, and Julian Trollor on behalf of The Department of Developmental Disability Neuropsychiatry (3DN)

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YOUNG REVIEWER:

HELENA
AGE: 15

People with an intellectual disability have lower intelligence than others and find it hard to do things necessary for day-to-day living, like communicating or taking care of themselves. There are different levels of intellectual disability, from mild to severe and profound. People with an intellectual disability often have many health problems, but it is often difficult for them to get good healthcare. They find it difficult to understand the complex language that many doctors and other health professionals use. Most health professionals have never learned how to treat people with an intellectual disability and they are not confident when they treat a person with an intellectual disability. Disability services and health services should work together as a team. Better healthcare for people with an intellectual disability is important, so that fewer people die because they did not get the healthcare they needed.

INTELLECTUAL DISABILITY

A neurodevelopmental disorder characterised by impairments in intellectual and adaptive functioning (for example, independent living) with onset during childhood.

INTELLIGENCE

The ability for problem-solving, planning, learning and understanding abstract concepts and to adapt to new situations.

WHAT IS AN INTELLECTUAL DISABILITY?

We all have things that we are good at and things that we might need help with. This is the same for people with an **intellectual disability**. People with an intellectual disability have lower **intelligence**, they learn more slowly than other people their age and have delays in their development. They can have problems with:

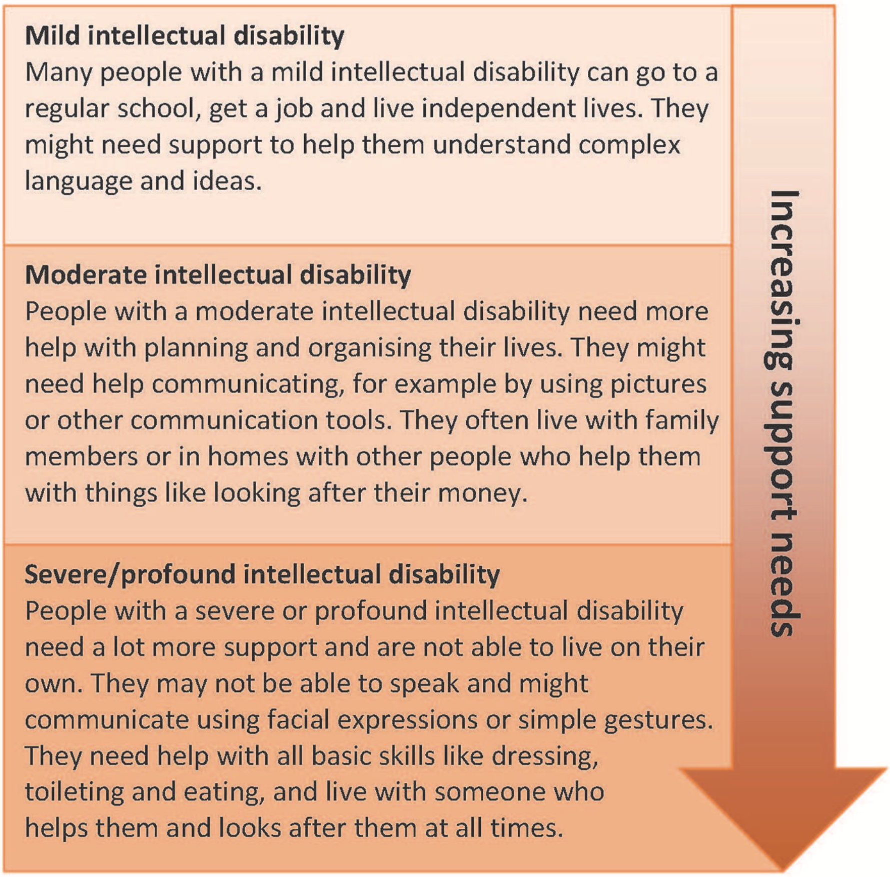
- Thinking
- Remembering things
- Talking and listening
- Moving around (e.g., walking and running)
- Controlling their feelings
- Looking after themselves (e.g., washing, dressing, and feeding themselves).

For people with an intellectual disability, these problems begin to occur in childhood, or before they turn 18 years old. Because of these problems, people with an intellectual disability might need extra help at school, at work, and at home. The amount of help they need depends on the level of the intellectual disability.

Sometimes, an intellectual disability can be an invisible condition. For people with mild intellectual disabilities, other people may not notice the intellectual disability immediately. Even those people whose intellectual disabilities are not noticeable still face challenges in their everyday activities and may need extra support.

WHAT ARE THE LEVELS OF INTELLECTUAL DISABILITY?

There are different levels of intellectual disability: mild, moderate, severe, and profound (see Figure 1). You may know someone with Down syndrome, which is the most common genetic cause of intellectual disability. Usually, people with Down syndrome have mild or moderate intellectual disability. Around 85% of people with an intellectual disability have a mild form. Many people with mild intellectual disabilities can go to regular schools, get jobs, and live independent lives. People with moderate intellectual disabilities need more help with planning and organizing their lives. They might need help communicating, by using pictures or other communication tools. They often live with family members or in homes with other people who help them with things like looking after their money. People with severe or profound intellectual disabilities need a lot more support and are not able to live on their own. They may not be able to speak and might communicate using facial expressions or simple gestures. They need help with all basic skills, like dressing, toileting, and eating, and they live with people who help them and look after them at all times.



Mild intellectual disability
Many people with a mild intellectual disability can go to a regular school, get a job and live independent lives. They might need support to help them understand complex language and ideas.

Moderate intellectual disability
People with a moderate intellectual disability need more help with planning and organising their lives. They might need help communicating, for example by using pictures or other communication tools. They often live with family members or in homes with other people who help them with things like looking after their money.

Severe/profound intellectual disability
People with a severe or profound intellectual disability need a lot more support and are not able to live on their own. They may not be able to speak and might communicate using facial expressions or simple gestures. They need help with all basic skills like dressing, toileting and eating, and live with someone who helps them and looks after them at all times.

Figure 1

Figure 1

Levels of intellectual disability and support needs at the different levels.

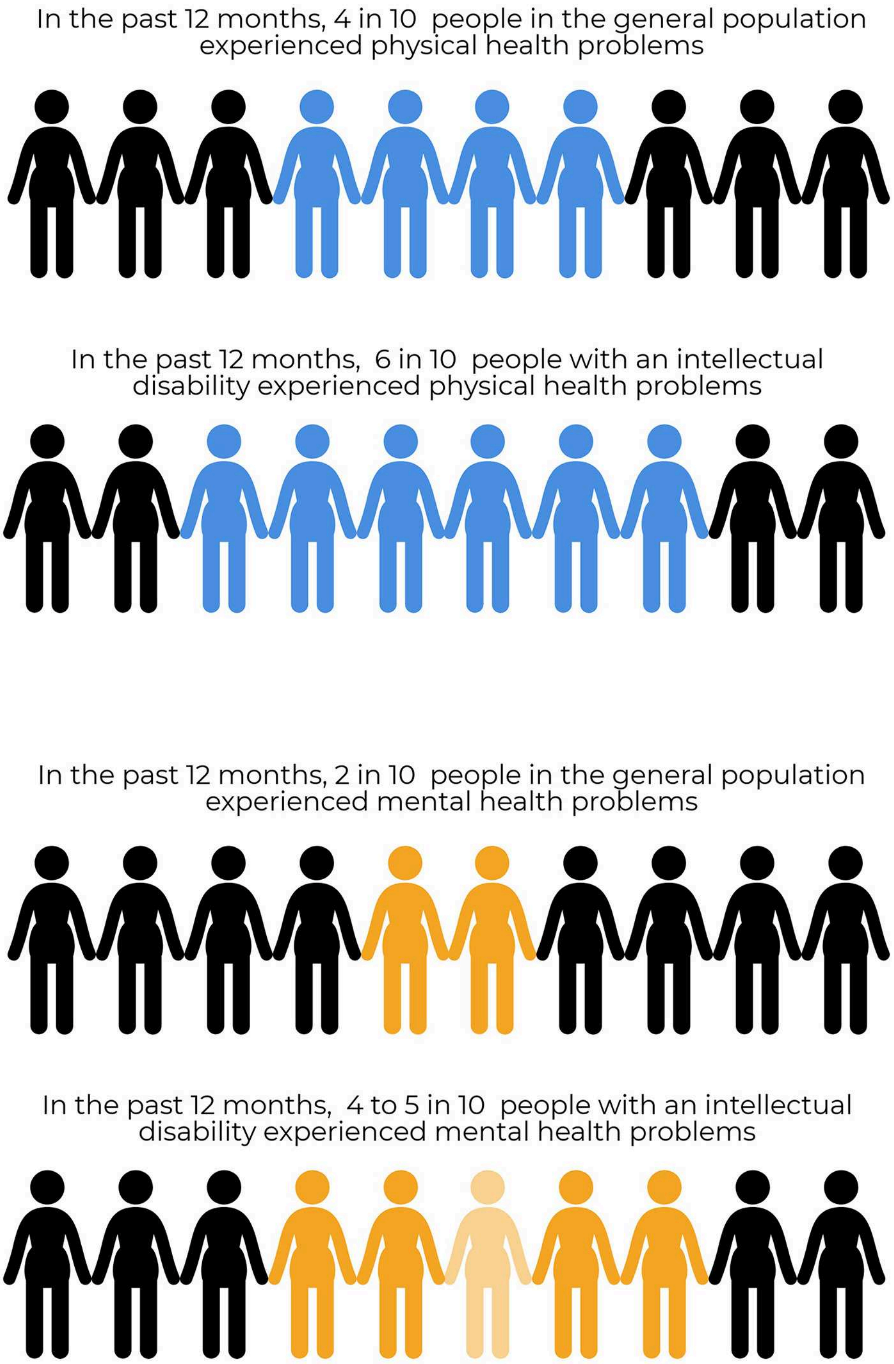
WHAT CAUSES AN INTELLECTUAL DISABILITY?

There are several things that can cause a person to have an intellectual disability. These can include genetic conditions like Down syndrome, problems during pregnancy or birth, an injury to the brain, or an infection or illness. Sometimes the cause of a person's intellectual disability might not be known.

HEALTH PROBLEMS IN PEOPLE WITH AN INTELLECTUAL DISABILITY

Most people with intellectual disabilities have a lot of problems with their health (see Figure 2). These can be physical health problems, such as:

- Heart problems
- Obesity
- Epilepsy
- Dental problems
- Vision and hearing problems
- Injuries (e.g., fractures)



In the past 12 months, 4 in 10 people in the general population experienced physical health problems

In the past 12 months, 6 in 10 people with an intellectual disability experienced physical health problems

In the past 12 months, 2 in 10 people in the general population experienced mental health problems

In the past 12 months, 4 to 5 in 10 people with an intellectual disability experienced mental health problems

Figure 2

Figure 2

Many people with an intellectual disability have more physical and/or mental health problems than does the general population.

These people can also have mental health problems, such as:

- Depression (feeling sad, down, or miserable most of the time or not being interested in activities they used to enjoy)
- Anxiety (inability to stop worrying about things, thinking situations are much worse than they are, having intense fears about things or situations, or having repetitive unwanted thoughts)
- Psychosis (believing or sensing things that are not real, for example seeing or hearing something that is not there)

People with an intellectual disability have more physical health problems than do people without intellectual disabilities, and they also have double the rate of mental health problems [1, 2].

Many people with an intellectual disability have more than one physical or mental health problem and need help from different types of doctors and other health professionals. Because of the high rates of physical and mental health problems, people with an intellectual disability often die younger than do people without an intellectual disability. One of our research studies showed that, on average, people with an intellectual disability lived until they were about 54 years old, while people without an intellectual disability lived until they were about 81 years old [3]. Many people with an intellectual disability have died because they did not get the best **healthcare**.

HEALTHCARE

Provision of medical care by providers such as general practitioners (GPs), medical specialists, allied health workers and nurses to maintain or improve physical and mental well-being.

WHY IS IT HARDER FOR PEOPLE WITH AN INTELLECTUAL DISABILITY TO GET GOOD HEALTHCARE?

It can be hard for people with an intellectual disability to find information about their health that they can understand. They can also find it hard to go to the doctor. Many doctors do not know how to speak to a person with an intellectual disability. Most doctors never learned how to treat people with an intellectual disability, so doctors are not confident when they treat a person with an intellectual disability [4, 5]. It can be difficult for a doctor to find out what kind of health problems a person with an intellectual disability has, especially if they cannot talk. Many doctors might think that a person is feeling or behaving in a certain way because they have an intellectual disability, instead of a physical or mental health problem. People with an intellectual disability often cannot tell a doctor what is wrong with them and they often have many health problems at the same time, which can be complicated to treat. Sometimes, health services say that they cannot help people with an intellectual disability, and that they need to go somewhere else for help. This is a big problem, because any person who gets sick should be able to get help easily.

WHAT DO WE NEED TO DO TO SO THAT PEOPLE WITH AN INTELLECTUAL DISABILITY CAN GET GOOD HEALTHCARE?

People with an intellectual disability, their families and caregivers, and other people who support them (e.g., doctors), all agree that we need to improve access to healthcare and services for people with an intellectual disability. Our researchers spoke to people about what health professionals need to do so that people with an intellectual disability get good healthcare (see Figure 3).

The people interviewed said that it is important that health professionals learn how to communicate and how to treat people

Figure 3

Figure 3

What health professionals need to do to improve access to healthcare services.

with an intellectual disability. Also, health professionals should make sure that a person with an intellectual disability understands the information that the doctor provides and is supported in making decisions about their health. Often, information about health issues is written in complicated language that people with an intellectual disability cannot understand. It would help if doctors and other health service providers would write information in simple language. **Disability services** and health services should work together as a team. Improving healthcare for people with an intellectual disability is important, so that fewer people die because they do not get the best healthcare. Further research into the healthcare needs of people with an intellectual disability is also important, to show which other aspects of the healthcare system need to be improved.

DISABILITY SERVICES

A range of support and services for individuals, families and carers, such as support to live independently, involvement in the community, assistance with employment and/or learning skills.

WHAT CAN CHILDREN AND YOUNG PEOPLE DO TO SUPPORT PEOPLE WITH AN INTELLECTUAL DISABILITY?

People with an intellectual disability may not be able to communicate the same way as people without an intellectual disability, but they still feel the same full range of emotions. Just like everyone else, a child with an intellectual disability needs friends and they need to do the same things other children are doing at school and at home. You should treat people with an intellectual disability the same way you would treat any other friend, by being open and kind. Tell a teacher if you see teasing or bullying happening at school. When you talk to someone with an intellectual disability, use short and simple sentences, and give the person enough time to respond. They might speak more slowly or get stuck on some words. Let them express themselves at their own pace and be patient. If you are playing a game or doing an activity, be friendly and include them in whatever you are doing.

When more people speak up for the rights of people with an intellectual disability it will help to make intellectual disability more "visible." This is an important step toward making sure that people with an intellectual disability are treated fairly and equally.

WHERE CAN YOU FIND MORE INFORMATION?

The Department of Developmental Disability Neuropsychiatry (3DN) at the University of New South Wales in Sydney does research to improve mental health policy and practice for people with an intellectual disability. This means we use the findings from our research projects to help government and health professionals to treat people with an intellectual disability in a better way. You can find more information about what we do and links to other organizations that help people with an intellectual disability on our homepage: `https://3dn.unsw.edu.au/`.

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YOUNG REVIEWER

HELENA, AGE: 15

My name is Helena and I am a rock n' roll queer teen! I enjoy all areas of Science. In my free time, I am also a song writer and enjoy playing the ukelele. I love the arts and most of the time I am painting and drawing.

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I am a Senior Lecturer and Researcher the University of New South Wales in Sydney, Australia. I study how mental health problems like depression are linked with cognitive disorders like dementia or intellectual disability. Through my research, I aim to improve health outcomes for people with cognitive and mental disorders. I enjoy working together with a range of people locally and internationally to tackle gaps in knowledge and to develop new knowledge that may lead to improvements in people's lives. When I am not researching, I enjoy traveling, going to concerts and spending time with my friends and family. *s.reppermund@unsw.edu.au

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RACHAEL CVEJIC
I am a Lecturer and Researcher at UNSW Sydney, located in Sydney, Australia. My research focuses on finding ways to improve the health of people with intellectual disability, dementia, and mental health problems. I am also a psychologist and have worked with children and adults experiencing different problems like depression, anxiety, and long-lasting pain after an injury. When I am not at work I enjoy gardening, seeing my family and friends, and spending time with my three cats.

JULIAN TROLLOR
I am a Neuropsychiatrist—a type of doctor who helps people with brain disorders that affect a person's thinking skills, emotions, or behavior. I see patients in a hospital clinic and I do research as a Professor at a university. My work discovers information about the health of people with intellectual and developmental disabilities, and what to do to improve health outcomes and health services. I like my job because it makes a difference to people's lives and helps to uphold the human rights of people with disabilities. When I am not working I love going on outdoor adventures, such as mountain biking, trekking, and cross country skiing with my wife and children.

HEALTH
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WHAT IS PTSD? DIAGNOSIS, TREATMENT, AND CHALLENGES

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AGE: 12


NOAH
AGE: 9

Post-traumatic stress disorder (PTSD) can occur when someone experiences a scary event or serious injury. This disorder can affect multiple parts of a person's life, from relationships with loved ones to performance at work. Unfortunately, PTSD is not understood well. It is considered an invisible disability, which means it can be difficult to determine if someone has PTSD just by looking at them, since they have no visible symptoms. Because of the difficulty of diagnosing PTSD, healthcare professionals are working toward checklists that can be used by all doctors for PTSD diagnosis and treatment, which will hopefully improve the care of PTSD patients. Similarly, disability activists continue to raise awareness and educate the public on PTSD. In this article, we will discuss the causes of PTSD, its effects on daily life, diagnosis, treatment, and the importance of showing kindness toward people with this invisible disability.

INTRODUCTION

POST-TRAUMATIC STRESS DISORDER (PTSD)

A mental health condition that develops after a distressing event and results in variable symptoms that impact an individual's life and relationships.

TRAUMA

A deeply distressing or disturbing event that may result in physical or psychological harm.

Post-traumatic stress disorder (PTSD) is a big term, but we can understand it by breaking it down. **Trauma** is a deeply distressing experience, like a physical injury or an emotional experience. "Post-" is a prefix that means "after," so "post-traumatic" means that a person has experienced something scary in the past. The final part of the term, "stress disorder," refers to problems that will affect the person afterwards. Putting it altogether, PTSD is a mental health condition that develops from a distressing event. PTSD does not occur in any one group of people or result from one specific type of incident; it can arise from various experiences.

People with PTSD might experience bad memories or nightmares that remind them of the previous traumatic incident. They sometimes also avoid people or places associated with the event. For example, veterans with PTSD might choose to avoid war museums because such places may remind them of combat. People with PTSD might also be especially sensitive to certain sights or sounds. Veterans might find fireworks disturbing, as the sounds may remind them of loud guns. Similarly, a survivor of a major earthquake might find a news report on another natural disaster disturbing.

Very few people who experience traumatic events actually develop PTSD. For this reason, researchers are working hard to figure out why some people develop PTSD while others do not. Scientists, doctors, nurses, and other healthcare professionals think development of PTSD has to do with the way that our external environments (such as where we live and our support systems) can interact with our genes. Previously, it was thought that PTSD was caused only by genes. However, we now know that our genes can be affected by everything around us. Some people are more likely to develop PTSD after a traumatic event if they carry certain genes. Some people might also be at risk of developing PTSD if the traumatic event turns certain genes on or off. Genes can be turned on or off, similar to light switches (Figure 1). A traumatic event can flip these switches just enough for a person to develop PTSD. Clearly, there are a lot of different factors that could lead to the development of PTSD. However, we still need to better understand these factors and their interactions.

EFFECTS OF PTSD ON DAILY LIFE

PTSD can have many effects on a person's daily life and relationships. Researchers have found that the more severe a person's PTSD symptoms are, the more aggressive the person's behavior tends to be [1]. People with severe PTSD may act out toward their friends and family or avoid talking about their feelings. At times, they may seem disconnected from everything around them, i.e., they might not respond if their friends and family try to talk to them. They may also

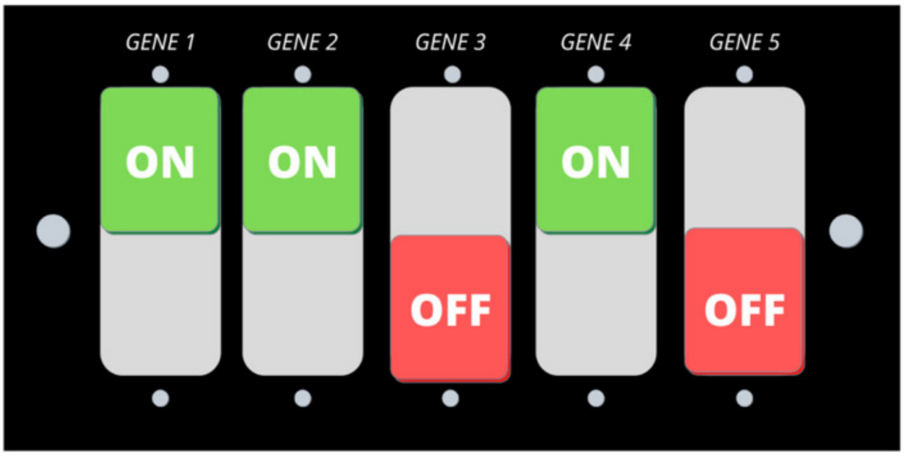

Figure 1

PTSD is believed to be caused by a combination of genes and environment. Genes can be switched "on" and "off," similar to a light switch. A traumatic event can sometimes flip these switches just enough for a person to develop PTSD.

avoid potentially triggering places or events, which can make going to friends' houses or birthday parties difficult. If people with PTSD do not explain why they do not visit, their loved ones may be confused and hurt. The effects of PTSD on daily life and relationships are challenging, both for people with PTSD and their loved ones, but resources are available. Resources, such as the National Institute of Mental Health (NIMH), a support group, or talking to a therapist can be helpful.

HOW IS PTSD DIAGNOSED?

There are several steps to determine if someone has PTSD (Figure 2) [2]. The first step is screening, during which the person is asked a few questions about their experiences. One common question set used in screening is called the Brief Trauma Questionnaire. This questionnaire asks 10 questions about serious life events, such as major injuries or anything that put the person's life in danger, to assess the level of trauma the person has experienced [3]. The second step involves using a universal checklist created by healthcare professionals and researchers to make an official diagnosis. This checklist is made up of criteria for diagnosing someone with PTSD, such as certain behavioral and bodily symptoms. The criteria can be found in the **Diagnostic and Statistical Manual of Mental Disorders (DSM)**, a book that lists and describes all known mental illnesses. For someone to be diagnosed with PTSD, that person must have had symptoms for at least 1 month. After diagnosis, doctors track the person's symptoms and response to treatment over time. This step includes self-reports that patients complete each time they go to the doctor's office. One commonly used self-report is a checklist from the DSM, which includes 20 questions about how often a patient has experienced different PTSD symptoms.

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS

A handbook that is used by healthcare professionals to guide the diagnosis of mental disorders.

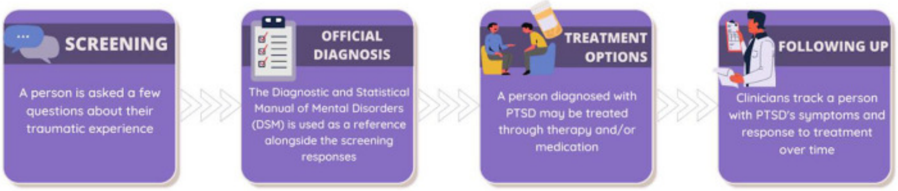

Figure 2

There are several steps involved in diagnosing and treating PTSD: screening, official diagnosis, treatment, and follow-up.

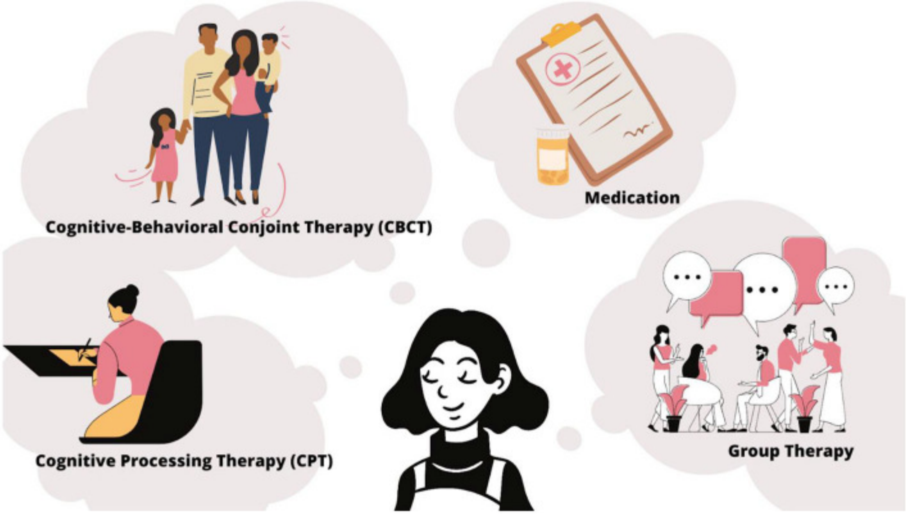

Figure 3

There are several types of treatment for PTSD. Examples include kinds of therapy called cognitive processing therapy, cognitive-behavioral conjoint therapy, and group therapy, as well as medications.

HOW IS PTSD TREATED?

PTSD treatments can include medications, individual therapy, or group therapy (Figure 3). In therapy sessions, people typically participate in specific types of therapy called **cognitive processing therapy (CPT)** or **cognitive behavioral conjoint therapy (CBCT)**. In CPT, people write about how their experiences have impacted their lives. The therapist helps patients pinpoint negative feelings and refocus their thoughts on the positive [2]. CBCT focuses on improving relationships by having patients work with their loved ones to improve problem-solving skills [1]. The other form of PTSD treatment is medication, which requires less time and effort from the patient, but must be taken under the watch of a healthcare team. Several medications used to treat PTSD are classified as **selective serotonin reuptake inhibitors (SSRIs)**, which are drugs commonly used to treat depression and PTSD. SSRIs have been shown to improve mood and decrease anxiety [4]. Unfortunately, there is currently no definite cure for PTSD. People living with PTSD might manage their symptoms by continuing medication and/or therapy, seeking family counseling, and consciously avoiding triggers.

COGNITIVE PROCESSING THERAPY (CPT)

An individual works with a therapist to identify and refocus negative thoughts based on writing about lived experiences and their impact.

COGNITIVE BEHAVIORAL CONJOINT THERAPY (CBCT)

A therapist helps an individual strengthen their relationships with others though improved problem-solving skills.

TRIGGERS AND TRIGGER WARNINGS

To keep PTSD in check, people with this disorder should try to avoid or mentally prepare themselves for situations that remind them of their traumatic event, known as **triggers**. In PTSD, a trigger sets off the stress response by reminding the person of the traumatic event, and can worsen PTSD symptoms. For example, violent movies with a lot of fighting can be triggering for a soldier who experienced war. Trigger warnings can help people avoid such triggers. Trigger warnings are notifications that warn people about potentially triggering types of content. They can be used at the beginning of certain movies, TV shows, or even TikToks. Trigger warnings allow people with and without PTSD to prepare themselves for the traumatic content, which can make viewing the trigger less shocking.

However, it is difficult to decide what should come with a trigger warning [5]. Take, for example, two movies that both feature soldiers in combat but have different titles. Should the movie with a clearly upsetting title, such as "Soldiers at War" or the one with a less obvious title, such as "Survival," come with a warning? The audience must also be considered. A book with triggering content might be popular in one country but unpopular in another. As a result, teachers in the first country may assume that their students with PTSD have heard of the book and decide not to provide a trigger warning. Teachers in the second country may assume that their students with PTSD have not heard of the book and provide the warning. For these reasons, psychologists and disability advocates are coming up with more universal ideas of what needs a trigger warning.

SELECTIVE SEROTONIN REUPTAKE INHIBITORS (SSRIS)

A type of medication that increases levels of a chemical in the brain that positively affects mood and emotions.

TRIGGER

Events or circumstances that cause a person to recall a previous traumatic experience.

PTSD IS AN INVISIBLE DISABILITY

Disabilities can fall under two main groups: invisible and visible. Visible disabilities, as the name suggests, are those you can see. For example, someone whose legs are paralyzed might have trouble moving normally and will need a wheelchair to get around. **Invisible disabilities** like PTSD are different, because you cannot tell whether a person has one just by looking at them. As a result, others may not realize that people with PTSD are different and may need certain types of help in daily life when compared to people without PTSD. For example, a boss might have two employees with PTSD but only "see" symptoms in one of them. The employee with the more visible PTSD may be allowed to leave work early each day to attend therapy, while the employee with the less visible PTSD must work as many hours as everyone else. The employee with invisible PTSD may have trouble focusing at work or finding time to attend therapy [6]. Moreover, if something is out of sight, it is often out of mind. Unfortunately, this means that PTSD often receives less attention from scientists and health care providers than many visible disabilities do. All of this tells us that, even though we cannot see invisible disabilities, it is important

INVISIBLE DISABILITIES

A type of condition that limits a person's activities, but may not be visible to others based on their appearance; a person who uses a wheelchair has a visible disability, while a person with post-traumatic stress disorder has an invisible disability.

to remember that the experiences of people who have them are just as valid as the experiences of people with visible disabilities.

CONCLUSION

PTSD is a disorder that people may develop because of their past experiences. It can cause changes in mood, emotions, and interactions with friends and family. A person experiencing these changes can be affected by others' opinions about the disorder, causing them to feel ashamed or uncomfortable. This can cause PTSD sufferers to hide their condition, attempting to be seen as "normal." Pretending not to have PTSD can lead to depression, anxiety, and other mental illnesses [6]. Therefore, it is important to be kind and respectful toward those with disabilities, visible or invisible. By treating people with PTSD fairly, we can make them comfortable enough to be themselves and speak openly about their disabilities. Ultimately, this will lead to a better understanding of PTSD and its effects, which can help increase awareness of invisible disabilities and ensure better lives for those affected.

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YOUNG REVIEWERS

ALAA, AGE: 12

I am a generalist and an avid reader. I love learning, traveling, and eating good quality cheese, pasta, and chocolate. In my free time I enjoy coding, drawing, coloring, watching cartoons and educational videos. My favorite sport is badminton. I am also a varsity badminton player and I love being on the court. In the future I aspire to work in the field of science or aviation and be a great role model for all the girls/women around the world.

NOAH, AGE: 9

I am a 9 year old kid named Noah. I like to code and read during my free time, and can type at over 40 words per minute. I like to play the piano, and know two guitar chords. My favorite song to play is "Turkish March," by Ludwig van Beethoven. When I grow up, I would like to become a teacher.

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I am a junior at the University of Texas at Austin pursuing a Bachelor of Science in Human Biology with a minor in Social Work and a certificate in Ethics and Leadership in Healthcare. In the future, I hope to pursue a career that incorporates social justice in the field of medicine. In my free time I love to dance, do puzzles, and read.

JANET Y. LE

I am a junior at the University of Texas at Austin pursuing a Bachelor of Science in Human Biology with a certificate in Ethics and Leadership in Healthcare. After I graduate, I hope to attend medical school and stay involved in biomedical research. In my spare time, I like to ski, try new restaurants, do arts and crafts, and explore parks.

PHOEBE LAY

I am a senior at the University of Texas at Austin, graduating with a Bachelor of Science and Arts in Human Development and Family Sciences, with a minor in Business. I hope to attend medical school and become a pediatrician. In my free time, I enjoy volunteering, running, cooking, painting, and getting artsy with graphic design!

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I am a junior at the University of Texas at Austin pursuing a Bachelor of Science and Arts in Biology and a certificate in Spanish for healthcare professionals. After graduating, I hope to attend medical school. I have strong interests in urban studies, public health, and community engagement. In my free time, I enjoy baking, playing tennis, and photography!

NICOLE OSIER

I am a principal investigator at University of Texas at Austin. I have bachelor's degrees in Nutritional Science and Nursing from Michigan State University, and a Ph.D. from the University of Pittsburgh. My goal is to better understand what makes some individuals recover better than others after head injury. My ultimate goal is to apply new knowledge to help doctors and nurses treat people with head injuries, so patients recover as well as possible. To learn more about my laboratory visit my publicly available website: `https://nicoleosier.wixsite.com/osierlaboratory/` or follow @osierlaboratory on Facebook, twitter, or Instagram. In my free time, I enjoy spending time with my spouse and cats and traveling the world. *nicoosier@utexas.edu

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