



DEIB Newsletter | March 2025

MARCH IS ...

DEVELOPMENTAL DISABILITIES AWARENESS MONTH

One in Six Children in the United States have a Developmental Disability

'Developmental Disability' is a very broad term used to describe a very diverse array of conditions. These can vary between learning impairments, intellectual impairments, or physical impairments. Some of these are well known such as autism or Tourette's. Some are less known such as Spina bifida or Noonan Syndrome. March is a time to educate and reflect on the challenges nearly 17% of our general populace overcome on a daily basis.

Down Syndrome

Every year, approximately 5,700 babies born in the United States are diagnosed with Down syndrome. This equates to about 1 in 640 births. The condition is named after John Langdon Down, who first described it in 1866. Down syndrome is caused by the presence of a third copy of chromosome 21 during fetal development. This extra genetic material leads to a range of physical and developmental differences as the individual ages. These can include distinct physical features, low muscle tone, heart defects, thyroid problems, and issues with hearing and vision. On a cognitive level, the effects can range from mild to moderate, often affecting the individual's ability to acquire complex skills such as speaking or retaining information. People with Down syndrome may learn at a slower pace, requiring more time to master certain tasks. However, individuals with Down syndrome often develop strong social skills, high empathy, and can be exceptionally warm with those around them. Contrary to common belief, people with Down syndrome can live fulfilling lives, holding jobs and even getting married. The care and understanding of Down syndrome has evolved substantially over the past century. In 1984, the average life expectancy for someone with Down syndrome was only 28 years. While it is still uncommon for individuals with Down syndrome to live into their 70s or 80s, the life expectancy for white individuals has increased to over 60 years in recent times. Despite advancements in medical care and therapies, this care is not distributed equitably. People marginalized by race often see their life expectancy significantly reduced, serving as a stark reminder of systemic inequality within our healthcare system.



Roy Frank Mitte III is an American actor, known for his role in AMC's 'Breaking Bad'. He was diagnosed with Cerebral Palsy at the age of three and advocates for actors with disabilities for the screen and stage.

Cerebral Palsy

Cerebral Palsy is the most prevalent motor disability in the world. Roughly one in 345 children have been diagnosed with Cerebral Palsy within the United States. Cerebral Palsy is a spectrum of various types and degrees that effect both movement and general posture.

Spastic: This is the most common of all types of the condition. This variant is represented by stiffness in the muscles and jerky movements.

Ataxic: This refers to a difficulty in coordination and balance and often manifests in shaky movements.

Hypotonic: This results in a significant lack of muscle tone.

Athetoid: This manifest as involuntary movements of the body. Individuals may make sudden motions like turning their body or moving back and forth.

Many individuals with Cerebral Palsy have a mixture of the conditions above. The affect these conditions have on a person's every day living can range from mild to severe. Over half of children diagnosed with Cerebral Palsy can walk without the need for assistance. Some individuals will require crutches or a hand mobility device, while nearly a third of Cerebral Palsy patients require a wheelchair. 42% of Cerebral Palsy Patients will also experience Epilepsy as a comorbidity. Cerebral Palsy is caused by an abnormality or damage to a developing brain, and can even occur after birth. While it can occur often in conjunction with the condition, less than half of Cerebral Palsy patients are diagnosed with any intellectual disability. It should be noted though that individuals with Cerebral Palsy are at increased risk for developing psychological or emotional issues as they mature. This can be attributed to societal barriers, be it the stigmas and assumptions able-bodied people make about them, or the physical barriers in place within society that make navigation within very difficult.

Spina Bifida

Around the 28th day of pregnancy, the brain and spinal cord are supposed to develop. A delay in this process can be indicative of a condition known as Spina Bifida. The words translate directly to 'cleft spine' and an estimated 166,000 individuals in the US are affected by the condition. There are four variants of the condition. The first is the most mild, Spina Bifida Occulta, Occulta meaning 'hidden'. This can often go undetected, with many people living their lives unaware they have it. This can manifest as a discolored mark on the spine or a dimple, generally on the lower spine, and usually is completely asymptomatic. The next type involves a closed neural tube defect. This has adverse effects on how the spine can collect fat and bone. While not often a visible form of Spina Bifida, the symptoms come in a wide range, from asymptomatic to incomplete paralysis. Meningocele is the third form of this condition, wherein the meninges of the spine begin poking through a layer of skin. Beyond the physical discomfort, this can also cause lack of control over bowel and bladder movements. Myelomeningocele is the most severe form of Spina Bifida. It differs from Meningocele in that in Meningocele patients the protrusion of the spine contains only fluid. In Myelomeningocele, part of the actual spine and its nerves are inside the protrusion and are damaged. Infants with Myelomeningocele are usually diagnosed via ultrasound. Surgery is something that will be required to ensure better quality of life, either while the infant is in the fetal stage or within 48 hours of birth. Infants with the condition are also at risk of developing what is known as 'Clubfoot', where the feet develop atypically. The child may need a corrective metal brace for the first few years of their life.

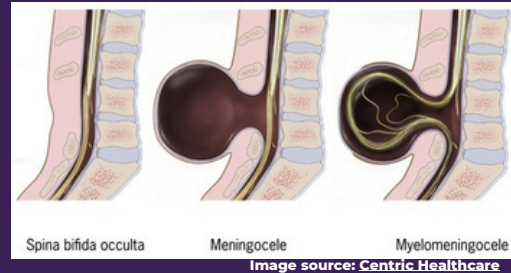


Image source: Centric Healthcare



Tourette's Syndrome

According to the CDC, 1 in 162 children may have Tourette's Syndrome. Tourette's Syndrome is a neurological disorder characterized by involuntary, repetitive movements and sounds called tics. These tics can be motor-based, like blinking or jerking, or vocal, such as throat clearing or speaking out of turn. The condition is believed to be caused by a combination of genetic factors and brain abnormalities, particularly in the basal ganglia, a part of the brain that helps control movement. This dysfunction is linked to an imbalance in neurotransmitters, especially dopamine, which plays a key role in regulating movement and behavior. People with Tourette's often feel a build-up of tension or an urge to tic, similar to the feeling of needing to sneeze or scratch an itch. While tics are difficult to control, some can suppress them for short periods, though this can lead to increased intensity later. Tics usually start in childhood, with motor tics appearing first, and tend to improve with age. While Tourette's is often associated with other conditions, like ADHD or OCD, people with the syndrome can lead fulfilling lives.

HOW WE TALK ABOUT PEOPLE WITH DISABILITIES

The language we use when discussing disabilities shapes how individuals with disabilities are perceived and treated by society. The disability community is diverse, and each individual may have different preferences for how they are described. Some people prefer "people-first" language (e.g., "person with a disability") to emphasize their humanity, while others prefer "identity-first" language (e.g., "disabled person") to affirm that disability is a core part of their identity. It's important to ask individuals how they wish to be addressed and respect their choice. By doing so, we show that we acknowledge their agency and identity. Certain terms, though often well-intentioned, can be condescending or dismissive, such as "differently-abled" or "handi-capable". These euphemisms downplay the reality of disability and can create distance rather than inclusion. Similarly, language that infantilizes or belittles people, such as "mad" or "crazy", can perpetuate harmful stereotypes about mental health or cognitive disabilities. People with disabilities should also not be portrayed solely as "inspirational" figures or defined by their disability unless it's relevant to the conversation. It's crucial that we avoid labeling individuals in ways that undermine their dignity or reduce them to their challenges.

Additionally, it's important to move away from offensive or outdated terms like "cripple" or "spastic". These words have historically been used to demean or dehumanize individuals, and it's essential to replace them with respectful, accurate language. Terms like "person with a developmental disability" or "individual with intellectual disabilities" are much more appropriate, as they honor the person first and their disability second. When we use language that accurately reflects a person's experience, we promote inclusion and show respect for their full humanity.

In short, thoughtful language has the power to challenge stereotypes and foster an environment where people with disabilities are seen and treated as equals. By moving away from harmful euphemisms and using terminology that empowers, we help to build a society where all individuals are recognized for their worth and their unique abilities. It's a simple yet impactful way to show respect and contribute to positive social change.