

President's Message – Harris Capps

Dear VOR Families and Friends,

Often, during disturbing portions of television newscasts, they end with inspirational stories of people who have gone out of their way to help others. I don't know about you, but I look forward to hearing these uplifting stories.

If we try hard enough, as we look back at our lives, there were probably times when each of us felt a glow of support as we tackled very demanding problems with our loved ones with intellectual and developmental disabilities. That person who left you feeling supported was essentially telling you, **"I've got your back"**.



Often unexpected help inspires us, motivates us, to find new ways to solve problems. And, as I think back, I am sure there were times that I wasn't even aware that a very real person helped make our special-family's life just a bit easier. At times like these, we begin to trust others just a bit more, we begin to open ourselves to the caring people who were always there... We just couldn't see them. When someone tells us, **"I've got your back"**, they know that helping you may not be easy... but they "step up to the plate".

Initially, helpers may not even know how to help us. But we need to be open to the very real desire people have to work on our behalf. You probably already know some of the people who **have your back**. Most Direct Service Professionals (DSPs) working at an Intermediate Care Facility (ICF) or coming to a small group home, or providing services at your home, really care about your loved one. They **have your back**. Many of these DSPs work for wages that are not proportionate to what they offer.

For almost 40 years **VOR, A Voice of Reason**, has worked very hard to **"have your back"** by tirelessly advocating for policies that protect and serve our loved ones.

A handwritten signature of Harris Capps.

Harris Capps

President, VOR Board of Directors

Update on the Build Back Better Act - VOR continues to advocate with Leadership of the Senate and the House of Representatives to have parity funding increases for ICFs and for the entire workforce of direct support professionals who provide loving care for people in ICF as well as HCBS settings.

Please see our website for more information.



We would like to share our sympathies with Bill and Marilyn Straw, for the loss of their son,

Robert "Bob" Straw

"A loving brother, a son, and a friend to all with whom he laughed and hugged."

VOR owes a great debt to Bob to and his family. His needs inspired his mother Marilyn to join up as one of our original members when we incorporated back in 1983. Marilyn served as President of VOR's Board of Directors over 20 years ago, during the time when VOR submitted its amicus brief to the Supreme Court, which has been included in the landmark Olmstead Decision. She remained a member even after Bob moved to a community setting. Marilyn is still an active member of VOR today, serving on our Membership and Development Committee.

Thank you, Bob, and thank you to all of our family members with I/DD who inspire us each day.

A Voice for Joshua by Vance Goforth

While this is extremely hard for me and my family to talk about, we realize that when we share Joshua's story, it's a way to help other families facing similar challenges by raising awareness of deficiencies in the current behavioral health care system.

Our amazing nephew Joshua was born December, 24, 2000, a healthy and beautiful baby boy. Twenty-nine days later we received the crushing and life-changing news that he had been the victim of child abuse and was in a fight for his life.



He coded while in ICU several times the first couple of days after the incident and the medical staff was able to revive him. Over the next few weeks with the swelling of the brain and hemorrhages behind his eyes, the outlook was not good. In fact, we were told more than once that the odds were that he would not pull through. Joshua did beat the odds and made it, but the Doctors were still telling us that he would most likely never walk, talk, see or hear.

After staying in the hospital for a little more than a month, he was released into foster care and we began to visit him. After Kristy discussed everything with me and I assured her that she had my full support, she decided to try for custody of Josh and start the adoption process. Kristy received custody of Joshua when he was three months old and soon realized that this was going to be a long and hard journey that would take the help and grace of God and the help of so many others.



The first six months Joshua had 30 to 50 seizures a day before they subsided when he was 9 months old. We enrolled him at Signal Center for his rehabilitation. and they did not focus on his condition or the odds of what he was facing, they just looked at what they could do to help him recover as much as possible. Today, through the grace and healing of God and the efforts of Signal Center, Josh is able to walk, see and hear. He continued to make progress over the next few years, but his neurologist warned us that he could possibly develop severe behavioral disorders as he grew older. We hoped that this would never happen but unfortunately it did, and severe aggression and self-injurious behaviors surfaced.

Joshua is now almost 21 years old. He has severe nonverbal autism, along with comorbid conditions like seizure disorder, cerebral palsy, bipolar and disruptive mood dysregulation disorder. The behaviors started in childhood. By 8 years old, issues at school got progressively worse and he was put on home bound after they became so severe the school system couldn't keep him safe anymore. We sought help through doctors and medications at first and then psychiatrists who recommended inpatient treatment ASAP. He was even accepted into a treatment facility only to be called the day before admission to be told that they couldn't treat Josh because we owned a wheelchair and their facility wasn't ADA compliant.

Everything started escalating during a trip to town a few years ago, Josh got upset and kicked out our van window and tried to crawl out at 55 miles per hour. I had to pull him back into our van and tried to keep him calm until we could get home. We decided to call a crisis number and see what they recommended. To our shock, they didn't know what to do, so they called the Department of Children's Services. DCS told us since this wasn't an abuse case, if we didn't see them in 48 hours then they weren't coming. So, there we were, making calls to agencies that couldn't help us, while facing crisis level behaviors on our own.

Josh's behaviors kept escalating and he was targeting our youngest daughter to the point that she was hiding daily from his outbursts. The nightmares really started as we began to call for help again. As we called crisis during these behaviors, we heard statements like, "We're not prepared for a child as low functioning as your son," or "If your son was suicidal then we could help." Yet again, crisis responders would leave and we were left to deal with these severe outbursts on our own.



We were advised many times to take Josh and "drop him off" at an ER department and let the state take custody. We were even told to get a divorce, because "it's easier to get help if the parents are separated." Needless to say, we didn't want to call crisis after some of these interactions. Finally, after much begging, the Tennessee Department of Intellectual and Developmental Disabilities came to our home and told us they would find us help. DIDD couldn't offer us anything until

Josh turned 22, so they called and set up an appointment with Children's Services. We were nervous about this because of the reaction we had before but we agreed to go to a meeting.

During this interview, we were asked why Josh was no longer welcome in our home. I explained that wasn't the case, we just needed help desperately. They requested documents from us and I provided them, but we never heard back. Joshua's behaviors had become daily at this point. After two weeks, I called DIDD and asked why they told DCS that Josh was no longer welcome in our home. They said, "You don't understand, if we didn't report it that way, they will never help your family." I was absolutely blown away after this. Not only did we not get help, they never followed up on the situation and he was getting worse by the day.

DIDD finally made a referral for Joshua to get into a new state program called ECF Choices in July 2016. He was accepted into this program and we were told he would get respite care, in-home services and other therapies and resources as needed. We thought yes! We're finally getting help! But days turned into weeks and weeks into months. My wife was sending emails to our coordinator begging for help but the reoccurring theme was "no providers available."

From 2016 to May 2017, the behaviors increased exponentially and had become very dangerous with severe aggression and self-injurious behaviors. In May of 2017, we still had not received the promised services and I was out of town for a conference when I received a call that Josh had a severe outburst and my wife had no choice but to call crisis again. This time crisis said that Josh needed help but couldn't find any facilities that had open beds. The crisis worker was extremely helpful but every path he tried was a dead end. Finally, he called DCS again. This did not go well for the situation. They came out while crisis was still at our home, and began interviewing our other children on our back deck as they watched through the window as Kristy was hit, slapped and kicked just trying to keep Josh from hurting himself. The crisis worker ended up apologizing for calling them because he said "I've never had an experience like this before," and he couldn't understand why the situation was being handled the way it was. After all of this, my wife and family were left alone with no help after he got his meds and took a nap.

The next day our coordinator said to meet her at a Knoxville hospital and they would get Josh treatment. My wife and father had to self-transport Josh even though we had voiced concerns about severe outbursts he had while we were driving. When they arrived, we were yet again turned away and told that the hospital couldn't provide treatment. Even though they would not treat Josh, they didn't want Kristy to leave with him over safety concerns. They also advised taking him to an ER and relinquishing custody in order to get help.

Finally, they got Josh home and he was accepted to a hospital in Georgia the next day. Again, my family had to transport him because an ambulance service refused to take him due to his aggressive behaviors. We explained to the hospital administration that Josh has always been very quiet around people he doesn't know, and that he will eventually get used to his surroundings and then the behaviors will manifest again. He spent 12 days at this hospital and was sent home because "they witnessed no behaviors." Four days later he was tearing our house apart and hurting himself severely. I made the call to get him back into the hospital but was informed, "it doesn't work that way." I was told he had to go through the whole process of being turned down by every treatment facility in Tennessee once again. This would take months and Joshua was getting dangerously aggressive.



At this time, we were provided with ABA therapy. It didn't take long for the therapist to see that Josh needed residential treatment and that was what they recommended. Our therapist eventually resigned and we didn't get ABA after that. We finally received one-third of the in-home services that he was supposed to get in September 2017 and the behaviors kept increasing over the next few months. He had got so severe that he had broken several teeth and had done over \$17,000 worth of damage to our home and vehicles.

My wife and I had become increasingly isolated from everyone around us during this time and we struggled to keep anyone from seeing how severe our son's behaviors had become. We basically had confined ourselves in our home, taking turns trying to minimize the behaviors as much as we could all while being told that help is on the way.

I cannot even start to describe what life was like during December 2017 through February 12, 2018. The behaviors had reached a level that can only be described as the worst hellish nightmare you could ever have. To watch your child that you love so much inflict so much harm upon himself is too much to bear. The strain this brings is indescribable and even that isn't an accurate description. The stress was building day by day.

On February 2, 2018, the nightmares went into overdrive. We were coping the best we could and trying to keep life as semi-normal as we could for our other four children. On that day, Kristy had stayed with Josh while I took our youngest son Camden to workouts. I was on my way home when I received the phone call. At first the call was totally indistinguishable from all the screaming that was taking place. My heart sank as I tried desperately to find out what was happening, then I figured out it was one of my daughters that had called and finally I heard "It's Josh" through the screams.

It felt like a shock of electricity went through me before I went completely numb. I had no idea what was going on, but I was trying desperately to just get home. I was crying and praying as I drove as fast as I could. Camden was crying hysterically and begging God to help his brother. I actually arrived before the first responders, and as I ran in the house Josh had just stopped having the most severe seizure we had ever witnessed. Kristy had called 911 when the seizure kept going to the point that Josh quit breathing and turned blue. He gasped for air and started breathing again just seconds before I arrived home.

Whatever happened during this seizure changed Josh and the behaviors became even more amplified than before. Over the next ten days, I can't even say we were handling the outbursts because that would be a lie. The behaviors reached a fever pitch that ended with extensive injuries to myself and Josh.

Josh had bitten his wrist until it was almost down to bone and began breaking all of his teeth off by hitting his head on the floor and walls. I was bitten over 50 times during three different outbursts and received lacerations, bruises and a severe black eye that may have caused permanent damage. Josh had extensive injuries from the self-inflicted behaviors and was not calming down at all. We visited two different ER departments during these outbursts and mobile crisis was contacted twice. Mobile crisis never did the face-to-face evaluation that is required by state guidelines.

We took Josh back to his doctor the next morning after being in ER rooms all night. His doctor forced the issue and made crisis respond. Josh was eventually transferred after a three-day stay in another ER room but we had to get lawyers and judges involved just to get the treatment he needed. After a few weeks and multiple legal issues, he was transferred from Georgia, where they had said before he wasn't having issues, to Springbrook, an acute treatment facility in South Carolina that specializes in Autism and related disorders. They are trained for comorbid behavioral disorders such as Josh has, and they quickly recognized the severity of the behaviors. He was in treatment there for 15 months.



When Josh finally received the needed treatment, he started slowly making progress. Springbrook was amazing. They not only treated our son but also encouraged and gave advice to the whole family. After 15 months of treatment, Josh was transferred to residential care at Orange Grove.

Orange Grove is a complete campus for individuals with intellectual/developmental disabilities. It's an ICF and HCBS provider that provides school, medical services, dental services and residential services. The fact Orange Grove is an established ICF has been the key contributing factor to Josh's success there. They are staffed and prepared for behavioral issues; even though he is in a group home setting, the knowledge and resources are still there. Josh has been at Orange Grove since 2018. He will continue in the school program until he turns 22, then stay on in the residential program.

We were in pure survival mode for so long, we didn't realize how much all of this had affected our other children and family members. Joshua's siblings love him dearly and were quietly trying to deal with the situation as they watched things that no child should have to ever witness. After Josh was in treatment a few weeks, they began to open up to us about everything and it hit us like a ton of bricks. We were so consumed by managing the behaviors and keeping everyone safe, that we didn't realize how much the stress was affecting all of us. Slowly but surely, the kids began to heal from all of the trauma, and we started seeing improvement in school and other activities.

When Josh finally received the treatment he needed, we created a Facebook page, A Voice for Joshua (<https://www.facebook.com/change4josh>). I was determined that I would advocate for issues affecting individuals like Josh who have severe ASD and comorbid conditions. I'm not the most eloquent speaker and my posts are usually more solutions-oriented than other bloggers who can effectively pull on heartstrings, but I'm determined to keep advocating and sharing his story until needed changes take place.

Our son Zach lives at the Glenwood Resource Center, in western Iowa. Zach needs the personal, person to person care that he receives at Glenwood. Below is a letter that we sent to Governor Kim Reynolds and Kelly Garcia, the Director of the Iowa Department of Human Services.

Good morning,

I want to let you know (once again) why I do not support my son moving into the community. We received a call from Marsha Edgington [Superintendent of GRC] last week regarding this. She said that Glenwood did not have enough room for more clients. I explained that there are empty buildings on campus. She then said there was difficulty getting staff which is the same problem community group homes have as well. Some agencies are forced to hire just to have a "body" at the house. These agencies are having just as many problems and concerns as GRC, and it doesn't appear to be a good idea to push clients out from GRC.

It was stated that a "less restrictive" environment is recommended. Please explain what that means – "less restrictive". There is a reason why my son is in a "restrictive" environment and it has to do with safety for him and others as well as his health. I do not know how you think a less restrictive environment would benefit my son or what that less restrictive is.

*I am told that my son is doing so well at GRC and that's why he should move out. My son is successful at Glenwood Resource Center and the reason for this is **because** of the staff and what GRC is able to provide him with. He has a job which is very difficult to have when living in the community. Many clients can't have jobs because of the community acceptance. Workshops that used to be available have now been closed and so these individuals instead of having a paying job are now sitting daily at day habs. My son at GRC has outings - more than his brother in a group home has. He has friends (and a girlfriend) at GRC and he has a paying job. This is what you want to take away from him. He has lived at GRC for 15 years and this is his home and community. I know that he is safe and he is staying healthy because of GRC. He has a much better life than if he lived in the community. My opinion is that GRC is a community.*

I have worked in group homes on very different levels and have worked with other agencies that support people with disabilities so I am very familiar with the community settings and supports available. I know there are many "success" stories but I can share more unsuccessful stories.

The staff in group homes are not able to follow doctor's orders or necessary diets because the clients can refuse and staff cannot do anything and that includes refusing to take medications. My son needs someone to do this for him because he doesn't understand the consequences of unhealthy eating or not taking his medications. I have another son who is in a community setting and because they are not able to help him with his diet and doctor orders, he now is obese and has fatty liver disease. I have a client that they were not able to assist with his meals and now he has diabetes. He now has been fighting sores and infection in his foot – he has had several toes removed and now possibly facing removable of foot and possibly his leg. This is NOT in the best interest for anyone with an intellectual disability – but it's a less restrictive environment for him.

I have dealt with a disabled son put in jail with general population and I will not go into details, but it was for 90+ days and we were only allowed to see him on a television screen for 15 minutes per week. What he did was pace back and forth in front of a store because he was upset. Someone called the police and even though staff explained to the police to let him work it out, the police put hands on him and of course he fought back. That's what the community setting did for my son – he wasn't a threat to anyone but he paid the price in more ways than one.

You can make community settings appear to be the best ever but I can guarantee from personal experience and experience with other families and disabled people that is not the case. As with anything, there is positive and negative in every situation.

If and when my son ever moves from GRC, you will not be responsible for him, we will. So that is why we are advocating that he remain at GRC. Your opinion is that he would do good in a group house and I disagree. It was stated that if it didn't work out in the community, he could come back to GRC. Who makes that determination? People get moved to different houses, different agencies and in some instances, out of state because the community wasn't able to serve them in what they needed but it was a less restrictive environment.

I am sure that I will be told that I'm the only one that feels like this, but I can guarantee, I am not.

Please accept our decision to not consider, investigate or move our son from Glenwood Resource Center.

Thank you.

Peggy and Larry Wright

“Unsustainable”

Executive Director’s Comments - Hugo Dwyer

In late January of 2019, I met with a freshman member of Congress in her D.C. office shortly after her inauguration. I was excited, because prior to her subsequent careers in education and politics, this woman had worked as a DSP in a large, state-operated ICF, the very one in which my brother had resided for over forty years. I was hoping that VOR might have a champion in Congress, someone who understood our families’ need for higher levels of care not found in most privately operated HCBS group homes. Imagine how my heart sank when I heard her utter ten words often repeated by the closure advocates who have dominated our state DDS meetings, “I believe that the state-operated ICF system is unsustainable”.

Unsustainable. I’ve thought about that word often since that meeting, and I have to disagree. Yes, ICFs are expensive, but that’s due to the fact that they provide care for the most vulnerable people, those who require higher and more costly levels of care. Yes, many states have closed their ICFs in the decades since the advent of the HCBS system, but that is mostly due to pressure from the outside, people who never needed ICF-level care, who advocate against the interests of those who do need it. And yes, by eroding the economies of scale of ICFs, these closure advocates have indeed achieved their goals of making some of these SOICFs unsustainable. But those that have managed to survive have managed to sustain the lives and well-being of tens of thousands of individuals with I/DD for decades. I know. My brother was very well sustained for 44 years in his home at Southbury Training School. And the staff, who were well trained and well compensated for this compassionate but demanding work managed to sustain careers lasting 10 - 30, even 40 years.

Unsustainable?

By comparison, just how sustainable is the system for Home and Community-Based Services? Certainly, HCBS covers a far greater number of individuals with I/DD, and has managed to provide appropriate care for many of them over the years. Nonetheless, many people with high needs are not receiving the levels of care they need. They don’t have access to 24/7 nursing, active treatment, regular dental care and other services offered in the ICF system. At the other end of the spectrum, many higher functioning individuals feel the HCBS system needs to offer greater opportunities for inclusion, both in residential services and employment. Many people are left out entirely, as waiting lists for HCBS services continue to lengthen. Many people entitled to services can’t get them, as there aren’t enough DSPs available to meet the demand. This is especially true for those with severe autism with violent behaviors who need at-home services. The HCBS system has been built on the model of hiring people at minimum wage and replacing them rather than retaining workers by offering salaries competitive with other employment opportunities in the state. The “DSP Crisis” that has arisen is not new. It has been the predictable and inevitable result of the way the HCBS system was constructed. We have replaced the safety net for the most vulnerable population with a private, for-profit system. *How is this even considered **sustainable**?*

President Biden’s Build Back Better Plan originally envisioned \$400 billion to remedy some of the deficiencies in the HCBS system. The intent was to reduce the number of people on waiting lists, which is currently numbers between 800,000 - 850,000 and to increase wages and training for Direct Support Professionals (DSPs) in HCBS services in order to address the crisis-level shortage of these vital caregivers that has been threatening the sustainability of the system for years. The House of Representatives saw fit to cut that amount down to \$150 billion. Is this really enough to sustain the HCBS system? Would \$400 billion have been enough? Or are we just throwing money at a problem without ever trying to find more effective solutions?

For centuries, people with I/DD (it went by other names in those days) either lived at home with their families, or were otherwise warehoused in restrictive environments that offered no treatment. That all changed a mere 60 years ago, when President John F. Kennedy signed two landmark bills that provided grants to states to increase mental illness and developmental disability programs, increased funding for prevention through maternity and infant care, and provided funding for the construction of facilities related to the care and treatment of people with intellectual disabilities.¹ In 1971, President Nixon passed an amendment to the Social Security Act that established and provided funding for special facilities, called Intermediate Care Facilities for Developmental Disabilities.² In 1983 President Reagan added another amendment to the Social Security Act to provide an alternative to larger facilities, the 1915(c) waiver. This created the Home and Community Based Services (HCBS) system for people who benefit from less restrictive care and integration with non-disabled individuals.³ While establishing these programs were all excellent, progressive means of helping people with I/DD live their best lives, it did create a divide among classes of individuals within the I/DD community and the services provided to oversee programs for their care, and a clash of ideologies that would erode family choice for ICF care.

In 2005, HCBS became a formal Medicaid State Plan option⁴, and in 2012, the split within the I/DD community was exacerbated by the creation of the Administration for Community Living (ACL)⁵, which combined the non-ICF component of the I/DD community with the members of the aging community, under the rather bizarre notion that their desire to live in smaller settings gave them more in common than the different manifestations of their individual physical, psychological, and behavioral needs and the treatment protocols required to address them. Since this time, we have seen a steady and



determined erosion of the ICF system, and economic policies that discriminate against the needs of the more severely disabled members of the I/DD community in favor of the aspirations of self-advocates and those more concerned with integration over treatment.

It would be wrong to say the problem is with the HCBS system, or with the ICF system. The entire DDS system as a whole has become a patchwork of good intentions and poor planning, good programs and poor oversight, inconsistent federal policies and disparate state programs, all hampered by a legacy of insufficient funding. What should have been a national, taxpayer funded safety net for our most vulnerable somehow evolved into a privatized system run by small non-profit and for-profit providers. In recent years, we have seen states further distance themselves from their responsibilities and hand over the care of our loved ones to large insurance companies whose managed care programs rely on denying services to individuals in need in order to meet their profit margins and keep investors happy. This is the system that has been allowed to develop, and this will certainly prove unsustainable.

But how do we create a **sustainable** system, in the face of all these problems and at a time when we see a growing tsunami of autism cases? Do we dissolve the ACL, and re-establish a system that treats the diverse needs and aspirations of the I/DD community? That's probably never going to happen. But we do need to speak out, constantly, to let our local, state, and federal officials hear the voices of those who have no voice themselves. Here are a few suggestions.

- Preserve forms of care and employment opportunities that work for our families, specifically ICFs and 14(c) programs.
- Insist on parity funding for all programs and services for all people with I/DD. Stop the erosion of services to some in favor of increasing programs for others.
- Educate those who oppose ICFs and sheltered workshops, so that they understand how the policies they promote often have harmful effects on those with the most severe intellectual, medical, and behavioral challenges.
- Develop our own alternatives, specific to the needs of those being closed out of ICFs or sheltered workshops.
- Work with hospitals, universities, university hospitals, large charity organizations, or endowment funds to create programs or facilities to deliver specific treatment services for our family members intellectual and behavioral challenges.
- Create state-level laws, like those recently passed in Missouri, that provide a state-funded equivalent to 14(c) certificates in the event that the federal government abandons the program.
- Increase the availability of dental services and training programs for dentists to better meet the needs of those with I/DD.
- Eliminate the CMS Settings Rule, or any provision in it that places unnecessary restrictions on I/DD housing by placing integration in the community over the need for providers' ability to deliver better quality care efficiently.
- Allow people with I/DD to seamlessly transition between ICF- and HCBS-type settings as needed, at different points in their lives, as we do with non-disabled people who move from protected settings to self-determination and back, as needed, as they change or age through life.

We cannot expect those who want to eliminate the services that work for us to come up with solutions that will work better. If there were such alternatives, we wouldn't need ICFs or sheltered workshops. They would disappear like pay phones and 8-track tapes. But instead of creating alternatives, our opponents have chosen to eliminate many of our choices through legislation. And quite often, they have succeeded.

It is up to us to stand up and speak out, not only for our families, and those families we know, but for future generations of people with severe and profound I/DD and autism. Whenever possible, try to attend meetings held by your state's Department of Disability Services. Meet with members of your state legislature. Develop first-name-relationships with all of these people. Join your state DD Council. Write a letter to your governor, or the director of your state Department of Human Services, like the one from Peggy and Larry Wright on the following page. All of this may be uncomfortable, and seem difficult, but it has been said that the most difficult thing to do is usually the right thing to do. As VOR President Harris Capps says in his opening statement, we all have to make sure we have each other's backs. It's the only way we can re-build a system that works for everyone and is truly **sustainable**.

¹ <https://www.jfklibrary.org/learn/about-jfk/jfk-in-history/john-f-kennedy-and-people-with-intellectual-disabilities>

² <https://www.vor.net/legislative-voice/legislator-toolkit/dd-act-reauthorization/item/icfmr-program-background-and-history>

³ <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html>

⁴ <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html>

⁵ <https://acl.gov/about-acl/history>

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Speaking out for people with
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Winter, 2021NL