

Advocacy at Mainstream Living



At Mainstream Living, we are grateful for the many volunteers who have taken time to make a call to a law maker or write a letter. As a group we have contacted every legislator and the Governor's office during the session. During our visit to the Capitol this session, members of the leadership team joined with me to share personal stories to and to introduce themselves to the lobbying process. Our efforts remain focused on working closely with our state association and our peers to request an increase in reimbursement rates, and to increase pay for our direct-care workforce.

advocacy is personal. Each of us has a responsibility to advocate for people with disabilities and their families. There are examples of this every day within our organization and just a few of those stories are featured in this issue. Thank you all for your work and support in being an advocate. If you have an interest in getting involved, please contact me at wjvaughn@mainstreamliving.org. We can always use another voice speaking on behalf of our members.

Thank you,

William Vaughn
President/CEO

In addition to formal lobbying efforts with the legislature and Governor, everyone plays a role in advocating for our members and families. Many of our leaders participate in weekly state association meetings to stay on top of current challenges and events. We meet with Managed Care Organizations, and representatives of the departments of Human Services and Medicaid Enterprises. Most importantly,

Advocacy is critical in the disability community and is one of the ways Mainstream Living works to empower our members and families. The thought of public speaking or being an advocate can be daunting, but it's actually a lot easier than you think. As an organization, we participate in formal lobbying with elected officials, but we also participate in very personal advocacy efforts for each of our members. There is a role for everyone to be an advocate.

The 2022 legislative session will end soon and we have had a lot of success thanks to the advocacy efforts of our Board of Directors, family members, staff and community supporters. There have been a lot of changes approved by the Iowa Legislature which will have a significant impact on our services for next year, including an increase in State participation in HCBS services. I have had a unique opportunity to serve as President of the Board of Directors for our State Association (Iowa Association of Community Providers) in addition to my role as CEO of Mainstream Living. This has allowed me a larger platform to advocate for closing gaps and increasing stability in our mental health and disability systems.



LOVE WHERE YOU WORK!

Now hiring compassionate and dedicated **Direct Support Professionals** to work with adults with disabilities in residential and community settings.

Full/part-time positions | No experience necessary



Meet Britt – Peer Advocate

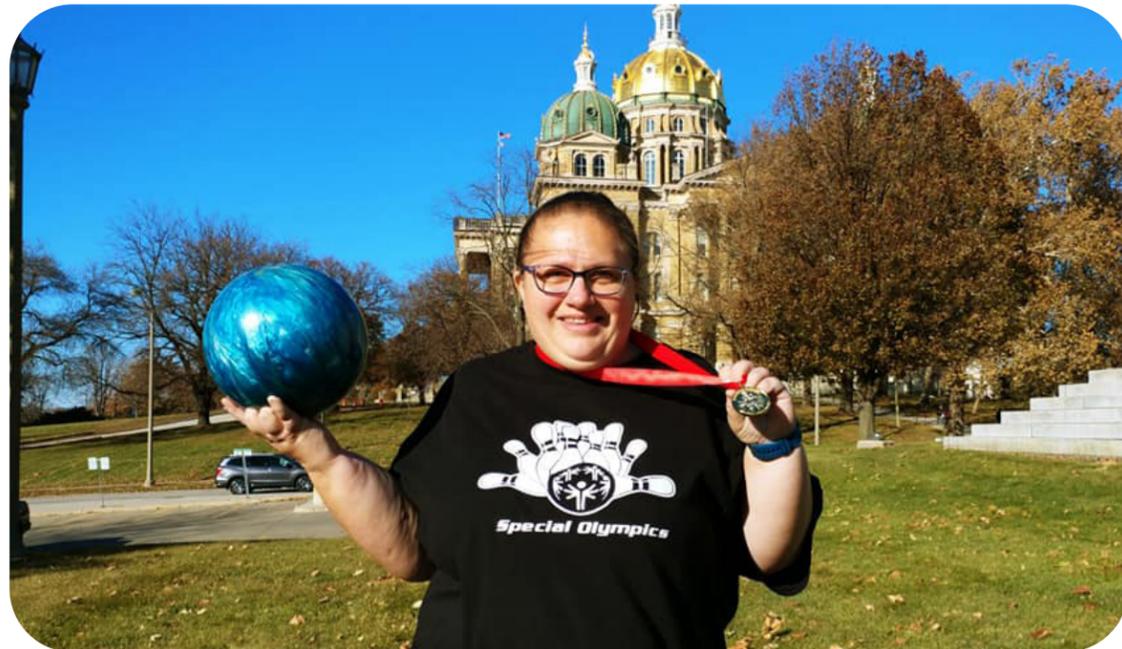
Britt Sandahl has been a Special Olympics athlete for 36 years, participating in snowshoeing, aquatics, bocce ball, softball, volleyball, flag football, bowling, cheer dance. In 2017, she became a Special Olympics Iowa Global Messenger in 2017 after being nominated by her friend Mary-Kate. As a Global Messenger, Britt helps to spread the message and vision of Special Olympics and share the benefits that athletes gain while participating. Britt says that she considers it an honor and privilege to be an advocate. "I'm proud to be the voice for the special needs community. That's part of my job as a Special Olympics Iowa Global Messenger."

In her role as a Global Messenger, Britt has given speeches at churches, schools, and many community organizations. She speaks about the impact Special Olympics has had on her and encourages others to become a part of the movement as participants or fans. Most recently, Britt was interviewed on local Iowa television, Channel 5 and Channel 13 to promote the Winter Games. During her interview on Channel 13, Britt wore the gold medal she won in snowshoeing and discussed her own positive experience in Special Olympics. While she has too many good memories to pick just one favorite, Britt does say that reuniting with friends is the best part of the events.

In her time as a Global Messengers, Britt has been a great advocate in communicating the enthusiasm and courage of Special Olympics athletes. Her own first-hand experiences make her the perfect person to share the message and spread the word. Britt's advice to those considering Special Olympics is to "go ahead and do so." There are 23 sports offered in Iowa and she encourages people to try a sport for a season or simply come to an event to cheer on the other athletes.

Britt is a wonderful advocate for people with disabilities. Although she has been a leader in the Special Olympics

movement for several years, she has more recently taken her advocacy skills to Link Associates, an agency that provides leisure and recreational services to individual with disabilities. Britt has been a guest speaker, discussing signs of depression and how to access mental health resources. Her desire to help others and speak up for people who may not be able to speak for themselves is admirable. We look forward to seeing what she does next!



Different is Beautiful

By Rylee Wolff – Family Advocate
Rylee is a high school student at Roland Story. Her essay is being shared with her permission.

Our society has made the word "different" a normal way to describe someone. The thing is, being different is a good thing, especially when we live in a world where we all blend together in one big blur. Each human personality exists inside of a framework composed of different qualities that are unique from each other. Being different can be acceptable if we change our mindset.

Growing up I never thought people's differences were an issue. The biggest obstacle I had to face was learning how to keep my mouth shut around people who were belittling others for their own sake. I had always kept my thoughts and opinions to myself, as my mom taught me. Most of the time individuals are so different from one another that it seems we get lost when there are traits that are more noticeable. That's where people get confused. If you stop and look around, we all have things that should stand out as weird, head-turning, or even confusing but, not all of us have faced the cruel reality of our world when it comes to being different. I once never had to worry about what I wore to school or how loud or quiet I was in a room full of people. This is simply because I never had a "reason" to stick out from a crowd. I'm just an everyday person as we call it. My sister Mallory wasn't a part of this crowd and still isn't and only for one reason. A reason we shouldn't even be considering in this day and age, and it's because she has Autism.

Mallory is the sweetest human to have ever entered my life, or maybe it was me who entered hers. She was born with Autism. If you aren't familiar with this term, it simply means a developmental disorder that affects communication and behavior. This disorder affects 1 in every 44 children daily. People who live with autism face struggles such as excessive rumination, obsessive-compulsive disorder, rigid routines and resistance to change, or even harmful mind and body thoughts. After

hearing that, I want you to picture yourself in her shoes. How would you feel not being able to fully control your emotions and actions? How would you react to hundreds of eyes being on you every day? How would you express your anger towards people who whisper mean things behind your back? Exactly. As Mallory walks through the halls in school, she never fails to smile at every person no matter what they've done or said to her. With that being said, kids have not always been easy on her. She has been called retarded, stupid, or mentally challenged. And it hurts. It hurts to the point where I want to just scream and protect her but, why should I have to? That's a question we need to ask ourselves. How is it fair that I have to worry day in and day out about what my sister is going through when I'm not around? I truly believe that with the power of our voices we as a community can make a difference in how individuals are treated.

The message I hope to portray to you is that it's okay to be different. We as a society need to better understand people with mental and physical disabilities. My grandma always uses the phrase, "People will never understand until it's under their own roof." Which is the closest thing to the truth but, you shouldn't have to face it to understand and accept things. Just be kind. Kindness can speak a million words to someone in need of it. Hold the door for someone, smile at a stranger, or compliment a person's outfit whether you know if they're different or not. I get it, it's not always the easiest to just go about your day when you see someone different, but hey we're all a little different in our own ways and that is exactly what makes being different beautiful.



Emily's Story – Staff Advocacy



In 2018, there was an opening at Aspen House in Ames. At the time, Emily lived with her parents in Des Moines, but made the decision to take the opening at Aspen. She adapted well and her parents were able to visit weekly, but over time, our RN Coordinator Trudy Luetters noticed that she tended to spend more time with staff rather than her housemates. Although there were no particular issues or conflicts with her peers at Aspen, Emily seemed more comfortable around the staff.

Several months ago, there was an opening at Knapp House in West Des Moines. During an HCBS leadership meeting, Trudy presented the idea of moving Emily to Knapp. Not only would

she be closer to family, but the ladies currently residing at Knapp House would provide for more interactive and meaningful relationships among a peer group. There were also more day programs in the area that would provide community integration options for Emily.

With the support of the team, Trudy contacted Emily's family to discuss how the move might prove to be a more positive environment. Her parents agreed and Emily was able to move to Knapp House in December of 2021. In just a few short months, Emily is loving her new home and making friends with her roommates. And with her family nearby, they continue their weekly visits.

Emily's success and ability to thrive in a community setting is just one example of the ways in which our staff advocate for members. Relationships that lead to positive advocacy are a key component in achieving our mission to enhance opportunities, create success, and fulfill dreams.