

One Family's Quest for True Integration and Person-Centered Care



Josh, 2014

Nelen Norcross is a firm believer in community integration and a person-centered approach to planning care.

She has been a lifelong advocate for her son, Josh, who has profound behavioral challenges, and recently quit her job in corrections/treatment to work for the Wyoming Independent Living Center.

She knows how integration should look for her Josh, but seriously questions whether the State of Wyoming does.

“ The Face of Inclusion?
We were all prisoners in our own home, completely isolated, Norcross said, describing how her family home was wired with buzzers to keep her family and neighbors safe. **”**

~ Helen Norcross

“For me, community integration and true inclusion means my son is provided with opportunities to live his life to the fullest extent of his abilities while keeping him and others in our community safe,” explains Norcross. “It’s about really focusing on Josh. It’s about person-centered supports, with an emphasis on the person.”

Josh’s early years

For years, Helen and her family attempted to strike a balance between integration and safety. This involved wiring her family home with buzzers so that they knew where her son was at all times.

“Josh’s disabilities make him unsafe for other people and animals,” shared Norcross. “We had a responsibility to keep our younger son safe, as well as our understanding neighbors. Still, to live with alarms that the whole neighborhood could hear if Josh went out the door was exhausting and stressful – and certainly did not mean ‘community integration’ for him.”

As Josh grew so did his challenges and needs. “We were all prisoners in our own home, completely isolated,” she said.

So, Norcross called in that promise made by the State so many years ago when they adopted Josh, only to find that he, along with about 500 other eligible Wyomians with disabilities, faced years of waiting.

Hope evaporates

In March 2014, after over a year of back-and-forth negotiations, the State had finally approved Josh’s waiver application as an “emergency case,” and, recognizing Josh’s profound needs, approved funding at the highest level of care and supervision allowed under the waiver.

With approval in hand, Norcross set out to find a provider willing to serve Josh. After 3 months of looking and rejecting providers, or being rejected by providers that did not have the staff or experience necessary, a quality provider was identified and willing to serve Josh and, much to the gratitude of the Norcrosses, also provide for day habilitation which his waiver funding did not cover.

However, Norcross’ diligence in finding the right provider for Josh’s needs – a person-centered approach to delivering services – backfired because not enough money was spent on Josh’s care while Norcross was looking for a provider. The Wyoming Behavioral Health Department assumed Josh did not need these services and significantly cut his approved funding.

Related News:

On page 9: The Department of Justice’s definition of “integration” raises questions

On page 9: Wyoming Task Force on Department of Health Facilities considers future of five state-operated facilities, each of which serves separate constituencies (veterans, I/DD, seniors, and mental health).

“No one thought to call me,” said Norcross. “I could have told the Department that the services were not used because I was still trying to find a provider. Josh’s needs certainly didn’t change. Yet, we were back to square one.”

She now wonders just how the Wyoming Behavioral Department defines “person-centered.” Having worked in treatment for so many years and also raising Josh, Norcross understands the person-centered approach better than most.

“My advocacy is critical in helping the State see that urgency [in getting people person-centered care], but what about other families who are suffering in silence? I worry about those people.”

~ Helen Norcross

“I’ve had intensive training in this approach and have seen it work with the most challenging individuals,” Norcross said. “It’s really about treating people like people and respecting differences in choices and needs.”

The Journey Continues

Norcross continues to advocate for Josh using a person-centered approach and will fight to make sure that all funding taken from his Plan of Care will be restored.

Still, she is frustrated by the fight and worries for other families who don’t know the system as well.

“Because Josh’s behaviors affect other people, putting the community at risk if funds are not restored, there should be urgency to getting him appropriate care,” said Norcross. “My advocacy is critical in helping the State see that urgency, but what about other families who are suffering in silence? I worry about those people.”

Norcross also questions how a “systems change” approach toward full inclusion and integration can also be person-centered care.

“‘Integration’ is being pushed as the ideal, but blindly so,” said Norcross. “My family home, wired like prison, is considered ‘integrated.’”

Norcross hopes her work with the Wyoming Independent Living Center will provide her opportunity to reframe the dialogue.

“We’ve lost sight of concepts like ‘community integration,’ and ‘person-centered supports,’” she says. “Families, advocates and elected officials must re-direct collective focus away from ‘bricks and mortar’ and back on each individual.”

“My son’s needs are unique and personal to him,” added Norcross. “What he needs and what I want for him will be different than another individual and another family. Our system must be responsive to individual needs and choice. I am a fighter and I do not give up. I will continue working to change that.”

VOR: “United, we are a chorus”

In separate editorials, Connie Howard and Shawn Humberston, VOR’s Wyoming Co-State Coordinators, have publicly called on families and advocates to work together and present a united front to face the challenges facing for people with disabilities in their state.

“It is our responsibility as citizens of this State to care for our vulnerable citizens: children, the disabled, and the elderly. We are the voices of the developmentally disabled,” Humberston wrote in letter published August 20, 2014 in the Lander Journal.

“While my advocacy is certainly motivated by son and his needs, I also recognize that he is one part of the bigger system,” wrote Howard in a 2013 Casper Star Tribune editorial titled “We must work together, not apart.”

Both object to the State’s plan to cut waiver services as a way to serve more people with less.

“While the State steps over a dollar to save a dime our families are being adversely affected,” Humberston wrote. “The State chose not to expand Medicaid; people are still waiting for services.”

The key, says both Humberston and Howard, is working together to expand, not decrease service options in Wyoming.

“Fragmented, we are just whispers. United, we are a chorus,” concludes Humberston.