Together for Choice Completes an Eventful First Year

Together for Choice was organized in 2017 by providers and families across the country seeking to enhance the right of individuals with developmental disabilities to choose where to live and how to spend their days. It has been a very exciting and eventful first year as TFC has made substantial progress toward its goal of enhancing choice. TFC stands for the proposition that individuals with developmental disabilities should have the same rights as everyone else to decide where to live, work, recreate and receive services.

TFC started the year with supporters in six states. But its mission has resonated throughout the disabilities community and TFC now represents providers and families in 26 states, with support growing each and every day.

In June, TFC met with the leadership of CMS to explain how CMS’s Settings Rule fails to recognize individual choice and limits the residential and vocational options available to individuals with developmental disabilities. Families explained how the Settings Rule has adversely affected their loved ones. These families had tried small homes in urban neighborhoods favored by the Rule only to find that these settings were extremely isolating. This isolation resulted in serious medical and emotional setbacks for their loved ones. The families, desperately seeking more appropriate settings, chose farmsteads for their family members. Their loved ones have thrived and are now healthier and happier than they have been in years. We explained to CMS how the Settings Rule discourages and discriminates against farmsteads, campus settings, and other intentional communities, even though many individuals with developmental disabilities find such settings best meet their needs and desires.

We provided CMS leadership with a proposed markup of the Settings Rule, showing how modest changes to the Rule could preserve its purpose of promoting community integration while respecting individual choice and expanding residential and vocational options. We next showed CMS that our concerns were shared by many families across the United States. TFC obtained letters from over 180 families explaining to CMS how the Settings Rule unintentionally negatively impacted their loved ones by interfering with the individuals’ ability to choose the setting that best meets their needs.

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One Family’s Choice

Wyatt enjoying family time at the beach.

When my twins, Wyatt and Lucy were born, everything was going smoothly and my husband, Steven and I were relishing in our new joys. Then at about age two Wyatt began experiencing seizures. With many interventions he was doing better, became seizure free, but had some brain damage. Then on a sunny Tuesday when my children were four, their dad went to work and vanished. I tried to explain in age appropriate ways what happened, but how do you explain terrorists crashing planes into buildings? Wyatt began suffering severe PTS.

After eight schools, even with gifted teachers nothing was helping Wyatt. Frightened for his future I researched various programs and finally found the ideal place: a working farm for young disabled adults. As Lucy was going off to college, I wanted Wyatt to experience his own sense of independence--his “college.” He went to Camphill’s Beaver Farm in Pennsylvania. He did so well that at 21 he is now at Triform Camphill Community in New York. I finally found peace of mind in securing Wyatt’s future. There’s enormous relief that we discovered the awesome Camphill Community, but it’s tempered because there’s a problem: Some decision-makers at CMS do not view our family’s choice as an appropriate one. CMS has adopted a rule, called the Settings Rule, that discriminates against settings designed for individuals with developmental disabilities, such as farmsteads.

When Together for Choice invited me to attend meetings on Capitol Hill to tell my family’s story and explain our choice, I said yes! It meant that I could speak for Wyatt and other individuals with intellectual disabilities. In my long journey advocating for Wyatt, I realized that only three populations are told where to live: prisoners, sex offenders and the intellectually disabled. Why are the IDD told where to live? That’s discrimination. The IDD and their families should have the same freedom as the rest of us--to decide where and how they want to live, socialize and work. I discovered that lawmakers needed more information about preserving the right to choice and expanding options for individuals with intellectual disabilities. We needed to work together to assure safe, meaningful and productive lives for the IDD and I was excited to engage in dialogue with members of Congress.
ILLINOIS TFC MEMBERS MEET WITH ILLINOIS CONGRESSIONAL DELEGATION

In November, under the leadership of Misericordia, a non-profit organization located in Chicago, Illinois and a leader of Together for Choice, providers, families and self-advocates headed to Washington D.C. to educate and engage policymakers on the importance of choice in the lives of individuals with intellectual and developmental disabilities. Thirty-two individuals from Clearbrook, Good Shepherd Manor, Little City, Park Lawn, and Trinity met with over 15 Illinois congressmen and congresswomen or their representatives and both Illinois senators.

The families and self-advocates shared their stories about the challenges that are faced when government policies fail to honor individual choice in living arrangements and vocational opportunities. Sister Rosemary Connelly, Executive Director of Misericordia, was clear in her message, “our purpose here is to redefine the definition of what community really means. Within that definition, individuals and their families should have choice of where to live, where to work and who their friends are.” One self-advocate who lived in the larger community and who made the choice to return to a campus setting because she felt isolated, confidently asked many of the legislators, “How can I help you understand that we are not an institution, we are a community?”

The vast majority of the Illinois congressional delegation was supportive of TFC’s message. This trip to Washington D.C. was the first of many that will take place to begin educating policymakers at the federal level that one size does not fit all, and that families and individuals deserve the right to choose among a wide array of quality options that best meet their needs.

Pictured: Sr. Rosemary Connelly, Misericordia Executive Director and self advocates with Senator Dick Durbin in Washington D.C. for the Illinois Day on the Hill
Together For Choice
Days on the Hill

In November 2017, families and service providers of Together for Choice from Delaware, Massachusetts, Michigan, Missouri, New Jersey and Texas traveled to Washington, D.C. to meet with the offices of their Congressional Representatives. Thanks to the amazing teamwork of advocates and Philip Peisch and Christopher Lowther of the law firm Covington & Burling, we had 29 productive meetings where families shared their powerful stories and explained the negative impact of the Settings Rule. The family stories were very well received, and many Members of Congress and their staff responded positively to our request that they write to CMS asking the agency to amend the Settings Rule and its guidance.

Every participant felt empowered and hopeful after these meetings, and they felt connected with other participants in the group. Our group dinner on November 29th looked and felt like a true family reunion after the Together for Choice conference in 2015!

Together for Choice will continue to work closely with Covington & Burling to obtain support letter from every office we met with. We would like to invite other families and service providers to join us in future Days on the Hill during 2018. These meetings with our government representatives are crucial for advancing the rights of individuals with intellectual and developmental disabilities to live, work and thrive in a community or setting of their choice! Please join Together for Choice and receive regular updates! http://www.togetherforchoice.org/join-now/

Pictured Top: Krista Mason and Peggy Driesenga with Congressman Huizenga; Middle: Together for Choice Days on the Hill Group Dinner; Bottom: New Jersey advocates with Congressman Chris Smith
Ryan Jennings graduated from a job focused transition program at 22 years old. After successfully working in many different training positions, only one company hired him for two hours a day, five days a week. Ryan got home from work at around 11 am, and did not have anything to do for the rest of the day.

Ryan was lonely, often sitting in his room playing on his IPad or listening to music. It was difficult to get him interested in extra-curricular activities because the programs offered were few, and very limited. Friends were hard to find, and it was difficult to coordinate outings together.

Other options to fill his day were sheltered workshops, or programs for special needs individuals; which cost approximately $200/day. Although Ryan has been on Illinois’ waiting list to receive home-based funding for over ten years, he was not selected to receive funding under the state’s lottery system. Ryan had participated in summer job camps on Misericordia’s campus in Chicago and really enjoyed them. He felt productive and loved being around many individuals who he made friends with. It was Ryan’s dream to live on Misericordia’s campus with many friends and choices of jobs and activities.

Ryan has lived at Misericordia for over one year now. At Misericordia, he works five days a week, 5-6 hours a day, including off campus volunteering two days a week at a nursing home serving food. He has learned many new skills, and has become more independent. At Misericordia, Ryan has many choices among the on-campus jobs that are available, including the restaurant, recycling, coffee packaging, laundry, and the bakery. Ryan also goes on weekly off-campus outings, which include job preparation skills such as interviewing and creating resumes. He has worked temporary off-campus jobs organized by Misericordia. He loves his jobs and is thriving. His speech articulation has improved, and his vocabulary has increased. I believe this is from being able to express and advocate for himself independently in a comfortable environment.

Ryan has many choices that he can make throughout the week in extra-curricular activities and is able to participate in many outings throughout the week. He lives in an apartment on Misericordia’s campus with four other men that are similar to him in age and ability. He loves being with them, and with the 56 residents in his apartment building that eat dinner together, have parties together, watch sporting events together on TV, bowl together, and go to outings and parties together.

At Misericordia, Ryan leads a life full of purpose with a robust schedule of many choices of friends and activities. He is not isolated or segregated. He and we have found that Misericordia’s campus setting best meets Ryan’s needs. We strongly support Together for Choice’s mission to ensure that individuals with developmental disabilities have the right to choose where to live and how to spend their days.
Meet the Board of Directors:

Scott Mendel, Chairman
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Geana Connelly, Secretary
Ashley Kim, Treasurer and TFC National Coordinator
Susan Axelrod
Kevin Connelly
Paul C. Landers
Sister Rosemary Connelly
Jim Whittaker
Joe Moore
In November, Together for Choice was invited, with approximately 20 other organizations, to meet with CMS Administrator Seema Verma to discuss the Settings Rule. TFC was the only organization at the meeting that spoke out in favor of an individual’s right to choose where to live and how to spend his or her day.

During 2017, we also met with numerous members of Congress on both sides of the aisle. In each meeting we had families and self-advocates explain the harmful unintended consequences of the Settings Rule and the importance of enhancing the individual’s right to choose where to live and how to spend their days. We received almost uniform support and many members of Congress have written CMS asking it to amend the Setting Rule and its guidance under the Rule.

TFC could not have accomplished all that it did in 2017 without the expert, pro bono assistance of Philip Peisch of the law firm Covington & Burling and the lobbying firm The Porter Group. We are deeply indebted to the invaluable services provided by these two firms.

We look forward to 2018 with great confidence as we continue to our efforts to enhance choice. We will continue to advocate for government policies and rules that provide individuals with developmental disabilities the same right as the rest of us to choose where to live, work, recreate, and receive services. We can only continue this important work with your support. If you have not already done so, please join Together for Choice by visiting our website at www.togetherforchoice.org and clicking on Join Now in the upper right hand corner of the page. We also welcome any financial support you are able to provide because our advocacy efforts do require significant financial resources. Please add your voice as we continue our fight for the rights of individuals with developmental disabilities.

Thank You for Your Support.

Scott M. Mendel, Chairman

Pictured: Phil Peisch, Scott Mendel, Judith Jackson, and Denny Rogers after meeting with the staff of Sen. Sherrod Brown in June 2017.
When my daughter Lucy heard that I was going to DC, she said, “I’ll come too!” She was most impact-
ful with her sibling perspective. Lucy explained that she wants her brother’s future set up in a way that 
allows him to do what he loves. For Wyatt, that’s being part of a rich and thriving community, with 
meaningful work, enjoyable activities (on and off the farm), many friends, caring people and where he is 
supremely safe. As Lucy says, ‘Why would anyone want to take his fabulous farm life away from my 
twin who has suffered so much?’

No one wants to institutionalize or isolate our children or siblings. We just want what we all want: the 
freedom to choose what is best and not have government bureaucrats decide where our family member 
may live or work. The freedom to choose is a civil right and a human right. I will continue to advocate 
for the right of my marvelous boy and his peers to choose what is best for them. I am so appreciative for 
the work of Together for Choice.

Lisa Paterson, a Warrior Mom.