

The Power of Advocacy

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In the summer of 2015, a determined group of individuals with no prior media or legislative experience accomplished a historic feat, the largest successful grassroots advocacy effort ever mounted in the State of New Jersey on behalf of the state's developmentally disabled community. The individuals were virtual strangers of varying ages and backgrounds, whose fundamental, and often only, commonality was a developmentally disabled child or sibling living in a residential facility outside of New Jersey. Nevertheless, these individuals advocated tirelessly together to persevere against unimaginable odds and defeat an ill-conceived program being promoted by a largely autocratic gubernatorial administration against their disabled loved ones. Together, these individuals changed the lives of hundreds of New Jersey's developmentally disabled residents for the better, demonstrating to themselves and others the power of advocacy.

In 2010, shortly after being sworn in as the Governor of the State of New Jersey, Chris Christie decided he would aggressively pursue a program that would affect close to 1,000 of New Jersey's developmentally disabled residents. The program, called the "Return Home New Jersey" initiative (RHNJ), had been quietly adopted -- but

never enforced -- by Governor Christie's pre-decessor. The goal of the program was seemingly simple: relocate all of New Jersey's develop-mentally disabled adult residents residing in out-of-state facilities to in-state group homes. The rationale publicly given for RHNJ was threefold: (1) to help address, at least in small part, New Jersey's recurrent budgetary shortfalls by saving millions of dollars annually (as New Jersey's in-state residential placements, in contrast to its out-of-state residential placements, would par-tially qualify for federal Medicaid reimbursement); (2) to improve oversight of those develop-mentally disabled residents living out-of-state; and (3) to enable greater geographic proximity of those residents to their families. Governor Christie assigned enforcement of RHNJ to New Jer-sey's Division of Developmental Disabilities (DDD), the state agency responsible for assisting New Jersey's developmentally disabled adult residents with residential and day programming; and, almost immediately, DDD quietly began the process of notifying families, a few at a time, that their disabled loved ones would be relocated in-state.

While some families perhaps welcomed the relocation news, most did not; a majority of the fam-ilies affected by RHNJ opposed it immediately. Those families realized that the resulting disrup-tion to their loved ones' lives from the relocations would be profound. Furthermore, they knew that the physical, intellectual, and emotional frailties of

their disabled loved ones, together with the uniqueness of their underlying disabilities, necessitated a residential program with housing options as extensive as their conditions. They knew that promoting a one size fits all residential program like RHNJ would be doomed to failure, as the vast intellectual, physical, and emotional needs of New Jersey's disabled community could not be met with a single residential model (i.e., a group home).

Understandably, those families were further frustrated that their disabled loved ones were forcibly being stripped of a right most Americans take for granted: the freedom to de-cide where to live. As a result, the families teetered in and out of despair regularly, horrified that DDD was aggressively pursuing these mandatory relocations with little, to no, regard for the health, safety, and well-being of their disabled family members. It was out of that despair, how-ever, that these families realized the necessity of organizing themselves to resist, and, if possible, to defeat, RHNJ.

Organizing hundreds of families spread across New Jersey (and, in a handful of cases, other states, due to family relocations over the years) was not easily accomplished. Several hurdles stood in their way. First, the families of loved ones resided at more than 30 out-of-state facilities throughout the United States, including states as far away as New Hampshire, Texas, and Wisconsin. In addition, the identities of those facilities were intentionally kept confidential by DDD (until a legislative

request mandated their disclosure in early 2015). Further, the families were largely unknown to each other, including families whose loved ones were residents at the same facility, because HIPAA and other constraints ensured, for better or worse, their loved ones' privacy. Nevertheless, one family ultimately decided to start an email group to educate families about, and discuss strategies to combat, RHNJ. By word of mouth, and over the course of several years, that email group grew exponentially in size, eventually reaching more than 100 families.

Once the families were in contact with each other, they began to organize themselves to push back against RHNJ's mandatory relocations. The lawyers in the group, only one of whom actually practiced disability law, started a separate email group dedicated to identifying and assessing the group's legal options; and they also educated and answered the families' questions about a myriad of topics, including state and federal disability laws, federal Medicaid residential placement reimbursement, and guardianship issues. Families with media contacts began to cultivate those contacts and educate the media about RHNJ, granting interviews whenever requested. In addition, the families organized themselves by legislative district and embarked on systematic outreach to their legislative representatives about the detrimental impact RHNJ would have on their disabled loved ones. Ultimately, the families' increased legal knowledge, media presence, and legislative outreach

led to several meetings with certain members of Governor Christie's cabinet (including the commissioners of DDD and the Department of Human Services) and also prompted legislative hearings on RHNJ.

In those meetings and hearings, the families were able to undermine RHNJ altogether, by negat-ing the three bases that Governor Christie's administration had proffered in support of RHNJ. The families demonstrated that little to no cost savings would result, or, in some cases, greater expense would accrue, upon relocating New Jersey's out-of-state developmentally disabled resi-dents in-state. Notwithstanding partial federal Medicaid reimbursement of the state's placement costs; the families dispelled the notion that greater oversight of their disabled loved ones would be achieved by DDD following relocation, as DDD had regularly failed over the course of sever-al decades to oversee most, if not all, of the more than 100 individuals at the largest out-of-state provider fewer than 10 miles from DDD headquarters. The families also showed that the in-state group homes being proposed for their disabled loved ones were often further away, and some-times more arduous to travel to (a significant concern for aging family members), than their cur-rent out-of-state facilities. Perhaps most importantly, however, the families publicly demonstrat-ed the sheer inhumanity of RHNJ, by publicizing case after case of the unthinkable: DDD trying to move disabled residents on hospice; DDD trying to move disabled residents with advanced dementia; DDD

trying to move disabled residents from the only homes they ever knew; and, DDD trying to move disabled residents who had happily resided out-of-state for decades -- often between 30-60 years.

Eventually, after years of tirelessly campaigning against RHNJ, the families succeeded in getting two separate bills passed by the New Jersey Legislature that would severely limit or completely curtail RHNJ. Unfortunately, the first languished, and Governor Christie vetoed the second. However, with media and legislative attention squarely focused on the inhumanity of RHNJ and the families' continued pressure to disband RHNJ altogether, key legislators -- including, surpris-ingly, some from Governor Christie's own party -- ultimately decided to attempt a veto override. While the override narrowly failed, it was nevertheless, a victory for the families, as Governor Christie was clearly losing the support of legislators within his party and his record of never hav-ing a veto overridden was jeopardized. Shortly after the attempted override, Governor Christie agreed to meet personally with a few of the families, presumably feeling the increased media and legislative pressure to curtail RHNJ. During the meeting, which included key legislators and DDD officials, the family members advocated against RHNJ; and, much to their surprise, Chris-tie heeded their advocacy and suddenly announced that mandatory relocations under RHNJ would no longer be pursued against a family's wishes. Additionally, and much to the

amazement of the families present at the meeting, Christie called for legislation to be passed which would protect the families from any future, compulsory relocations of their disabled loved ones from their out-of-state homes. Simply put, RHNJ ended as quickly as it began -- in a moment -- and the families were assured that no future relocation program would ever be pursued with their dis-abled loved ones.

In attaining the victory, they had sought for so long, the families learned an invaluable lesson: advocacy works, but unwavering determination, perseverance and courage are essential to its success. In emotionally charged situations, like that involving RHNJ, determination, persever-ance, and courage are not easily maintained over long periods of time. Having more than 100 families in the group helped tremendously, however. When one family's energy was depleted, which inevitably happened for every family involved from time to time, another family was ready, willing, and able to continue the fight -- to meet with legislators, contact the media, and attend and testify at legislative hearings. The families' incredible support for each other through-out the entire process was, in large part, the reason for their success -- they enjoyed strength in numbers and they rallied each other when needed. Given the emotional journey the families took together, it is not surprising that they remain close to this day and their email group remains ac-tive. Undoubtedly, the families who fought against RHNJ are a testament to the

power of advo-cacy.