Why Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) should remain open and why an ICF is the best option for my sister, Rosemary…

By Joanne St. Amand

First and foremost, I believe families and guardians should have a "real" choice of residential options for their family members with Developmental Disabilities/ Intellectual Disabilities/Autism (DD/ID/A). And, to have a "real" choice, there needs to be "real" options, not just a group home or a nursing home! Second, everyone with ID/DD/A does not require the level of care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) to survive or thrive.

Rosemary and me

Rosemary will be 70 years old in a few months. She is the youngest of three. Our older brother, Anthony and I are her co-guardians. Rosemary was born profoundly intellectually disabled, a complete surprise to my parents because nothing was unusual about her birth. Typical of the doctors at that time, they advised my parents not to take Rosemary home from the hospital. My parents ignored their advice, and my mother went to the hospital every day for the next 3 months until Rosemary could feed from a bottle. As soon as she could, the feeding tube was removed, and Rosemary came home.

Rosemary needs help with every aspect of her life. My parents lifted and carried her everywhere. My mother pureed her meals with our kitchen blender and one of us would feed her. Rosemary lived with our family until she was 20. Then, my mother began having health issues. So, our parents made the difficult decision to look for a placement for Rosemary. They wanted to find her a home that provided the care and services she needed while they were still young enough to be active in her life, watch over her in her home, make changes if needed, and not leave such responsibility to Anthony and me.

My parents explored all the options and made an informed personal choice to place Rosemary on the waitlist for admission to a NJ state-operated developmental center, a federally licensed ICF/IID) She was admitted within the year.

An informed, personal choice in residential settings…

Our family's choice for my sister, an ICF/IID, is the most comprehensive program offered by the Centers for Medicare and Medicaid Services (CMS). At the heart of this program is something called an "Active Treatment Plan." Only federally licensed ICF/IID programs offer this. Any facility, whether it is a large state-run center, a smaller privately run facility, or even a 4-bed group home, can acquire this licensing from CMS, if they meet the "Conditions of Participation" required by CMS. It is the ICF "program with services" that is crucial, not the bricks and mortar of the buildings where the services are provided. Why am I stressing these points? Because we are being led by ideologists, protection & advocacy agencies, disability advocates, and people with vested financial interests in the *business* of developmental disabilities that everyone does better "in the community." This is not true. Closing ICF/IIDs would be the biggest cut-back in someone's medical coverage and services imaginable for an individual who cannot live without them. Rosemary is someone who requires the level of services provided in an ICF/IID licensed program to live a good quality of life.

Rosemary with my brother Anthony

The SOS of options ……

No one is prepared for this journey. No one chooses to move their child out of their home without tears and heartache, even when they know it is the best option for all concerned.

When I think of an ICF for Rosemary, I think **SOS**…. **Services**, **Oversight, and Socialization.**

Services are what keep Rosemary healthy and thriving. She is surrounded by trained direct care staff with many, many years of experience, two on-site doctors experienced in treating individuals with IDD and autism and a plethora of medical conditions, nurses on every shift, speech and occupational therapists, a nutritionist, dental hygienist. Although Rosemary is nonverbal, her speech therapist plays a critical role in her well-being by monitoring her dysphagia and determining the appropriate moisture level and texture of her pureed food. Together with her nutritionist and medical team, Rosemary's weight has

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been maintained and the risk of aspiration minimized. And they established a backup plan for the days she does not want to eat so she continues to get enough fluids and calories. This is so important because as soon as Rosemary is not feeling well, she does not want to drink, often gets dehydrated, Her sodium levels spike and protocol send her to the hospital for hydration. Her three ER visits this year were traumatic for her. Her veins are small, so it takes multiple attempts to put in an IV line, and often she ends up with a PICC or midline catheter. Nothing is straightforward for Ro, or for thousands like her.

Anthony and Ro

Oversight is important, and especially so because Rosemary cannot communicate. She cannot tell you if she is sick or in pain, hot or cold or if something is wrong. Her ICF/IID must abide by the CMS State Operations Manual for ICF/IID, Appendix J, a 247-page document which contains guidelines for everything from the minimum and maximum temperature of her food or bedroom, to staffing requirements, to the members of her Interdisciplinary Team (IDT) who develop her personalized "Active Treatment" plan. The IDT thoroughly evaluates Rosemary's abilities and sets goals. They recommend a program to assure her well-being and promote improvement in her abilities. One such recommendation is that a staff member must have "eyes on Rosemary" at least once every 15 minutes. For Rosemary who needs help with every aspect of daily living, one goal is to be able reach for and hold an object like a fork, so one day she may be able to feed herself, or for her to make some decisions like a nod if she wants to wear a certain outfit that day. Rosemary's IDT consists of a staff member from each area (medical doctor, dental hygienist, direct care, nutrition, recreation, PT, OT, psychology, social worker, etc.,) usually between 10-15 people who sit in a room with me and Anthony (we are her co-guardians), at least once a year. Unique to an ICF/IID is the "Active Treatment" plan. No other program or facility offers an Active Treatment plan like that required of an ICF/IID. They may say they do, but they do not. The Active Treatment plan is comprehensive and is what requires the ICF to provide sufficient, needed interventions and services, such as doctors, nurses, therapists, etc. on-site as well as much, much more.

Our parents chose the ICF/IID for Rosemary's new home because it is the only place where the government mandates this level of care. Rosemary and the others who are profoundly or severely intellectually disabled and require this level of care make up only about 5% of the entire population with ID/DD/A. The overwhelming majority are diagnosed with mild or moderate ID/DD/A. However, it is still imperative that we preserve the ICF/IID program so it is available, and those individuals and families can choose it for their family members who require this level of care.

Socialization is a less tangible but important aspect of Rosemary's wellbeing. Once, while walking the grounds of Ro's ICF with a NJ legislator, I was asked if the services Rosemary required were present in the "community" would my family have chosen a group home over her ICF. I told her I did not think so. First, the level of staffing, on-site doctors and 24-hour nursing at Rosemary's ICF could never be matched in the "community". Also, Rosemary is with her peers. These are her friends, just like students in a dorm at a college or senior citizens in a gated community. People like to be with people like themselves. Why not this population too? When I visit Rosemary, she looks for her friends. Her eyes follow the other residents as they stroll or roll down the hall. Rosemary's focus moves away from me when she sees her friends go by.

My husband Bob and me with Rosemary

As part of the Active Treatment plan the ICF must have professional program staff trained in recreation. Ro's center has an entire recreation department. At her recent IHP meeting, her recreator informed the IDT that Rosemary participated in numerous activities during the year both in-house and in the "community." Birthdays, holiday parties, dances, cookouts, Family Day, and textile activities are celebrated. Rosemary went to the mall, the movies, a petting zoo, and local attractions like "Northland." Her social life is very full!

Rosemary's ICF/IID successfully addresses every part of her life and has done so for almost 50 years. We are grateful for VOR and all its members past and present, for their many years supporting and protecting those with DD/ID/A and having real choice in residential settings. My brother Anthony and I are proud that our parents made the right choice for Rosemary, and we will be forever at her side.

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