

Guest Column

Intentional communities help adults with IDD

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| By [Mary Mullett](#) |

One thing almost every person desires is the ability to live independently while remaining connected to a community of friends and peers.

For some, this goal is easily attainable; it's just the natural flow of life. For adults with intellectual and developmental disabilities (IDD), however, this goal is not so easy to achieve.

Many such adults live fulfilling lives at home, engaged in activities and outings, guided by the love of parents who understand their limitations but also the possibilities before them.

Every day, we field calls from parents wondering what will happen to their adult children when they are no longer here. Who will help their adult children with disabilities live satisfying, fulfilling lives with as much independence as they've experienced in a loving, family setting?

The options we have today in Michigan are limited. Either a person lives in an adult foster care (AFC) setting or receives state funding for the support that allows them to live somewhat independently with caregivers. There is no middle ground, and for today's active, forward-thinking parents, that's just not good enough.

At Samaritas, we serve 172 adults with IDD in 12 group homes, and in our At Home Support Services throughout Michigan. We also provide stable, secure, affordable housing to more than 1,200 seniors, families and individuals. National research reveals that in many American locales, waiting lists are growing for people with IDD to find housing and community living support; in some instances, access to support is not only delayed but even discontinued.

Estimates put the number of children with developmental disabilities at 1 in 6, or 15 percent of the population, and for all Americans, the number is somewhere around 4.6 million. One report estimated that more than 1 million people with IDD wait for services that may never come. The need is clearly great, and the time is now to figure out flexible options for such a sizable part of our population.

Since the 1970s, we've moved away from an institutional model of serving individuals with IDD toward a more personal approach to integrating them into community life. Still, 58 percent of parents serve as caregivers for their children with IDD, providing more than 40 hours weekly — and sometimes double that — of support and care for their loved one.

They endure exhaustion, stress and guilt a good chunk of the time because they worry they can't do enough. And what happens when these parents age and are no longer able to provide this level of care? I'm not convinced our current systems adequately support this population.

We must establish better options. It's not just about placating aging parents or alleviating anxiety about the legacy they can leave to their adult children with disabilities.

It's about empowering every member of society to be contributing, productive and generative — leading to a personally satisfying life. This lifts all of us up.

At our group homes and Affordable Living (AL) communities, we offer classes, activities, transportation coordination and other opportunities to create engaging situations where every resident feels welcome and they are contributing. It's easy to do when a position is funded, which happens with AL service coordinators or direct support professionals in AFC homes.

Some people need around-the-clock care. Others might need a few hours a day. Support comes in the way of activities of daily living, meal preparation, bathing or simple community integration so no one feels isolated or alone. If you don't qualify for AFC or for support in your private home, what then?

Some parents want us to create intentional communities with a more familiar feel, so their adult children can transition well and integrate completely. If only we could find a way to provide a community with extra support, beyond what is funded today, without breaking the bank.

It's difficult to develop a bottom line that supports itself. Dynamic parents who know there are possibilities for their adult children dream of a larger community of integrated residents — neurotypical people alongside people with IDD, all sharing a real intent to build community and support one another.

But current funding models in Michigan don't allow for such visionary possibilities. At least not yet.

We want this not just to satisfy parents but because it is the right thing to do. This type of interdependent community setting brings more access to more activities. Residents with IDD can grow their skills, gain independence, become employed and increase their quality of living. They give back and benefit others. And the positive effects ripple on and on.

As a nation, we have fallen short of creating an America where all people are accepted and supported toward achieving their full potential. Families want their loved ones with IDD to live in a community with people they choose to live among.

And why shouldn't they?

We desire to create and implement innovative models throughout Michigan where we can keep costs low, allow for choice and voice of the most vulnerable needing support, and provide the care and coordination each individual needs to reach their full potential. We strive to find a way every person can give back, sharing their gifts with all.

Hopefully, working together, we can get there.

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