

PACID: PARENT ADVOCATES FOR ADULT CHILDREN WITH I/DD
4/3/17

BACKGROUND

Adults with intellectual and/or developmental disabilities (I/DD) often live at home with aging parents, unable to access the system that offers affordable housing and Medicaid benefits. Parents worry endlessly about what will happen to their child when they are no longer around or able to take care of them. Such is their angst that many jumped at the chance to become part of a grassroots movement that offers information and education about Medicaid waivers and housing options.

The group, Parent Advocates for Adult Children with I/DD (PACID), started last September with a handful of parents and now numbers over 130 families. It is free, open, and receives no funding. Most families are from Orange County but a few are from as far away as Chatham, Durham, and Wake counties. PACID's goals are to create a space where parents can network, identify housing opportunities, profile the needs of the adult I/DD population, and advocate for those needs.

With a survey return rate exceeding 60%, PACID found that:

- Virtually all of the adult children are living at home.
- About half are on the autism spectrum, almost all of whom are male.
- Half of the respondents do not have a Medicaid waiver, and some have been waiting for more than a decade.
- About half of families without a waiver have not even applied, some because they feel it's hopeless and some because they've never heard of the waiver.
- Of those that do have a waiver the average wait was about 5 years.
- Over half want their adult child to move into their own place in less than 5 years.
- A solid majority want an in-town rental and are amenable to having a roommate for friendship and for the necessity of cost-sharing.

Care needs varied widely.

- Only 20% anticipated their adult child would need 24-hour/day care.
- Another 30% thought their child needed fewer than 5 hours per day.
- The rest--50%--said their child would need 5-14 hours per day or less.

Specific needs were all over the map, from a group home all the way to independent living (with minimal supports). But one theme was shared by all—the need for a lifestyle that includes friends and neighbors. This shouldn't be surprising. A home is just a shell of loneliness without the means to access friends and activities. For adults with I/DD that means daytime supports and, often, living in close proximity to friends who are themselves disabled, and working or playing in the wider community. They seek what any typically developed person would want—connection. A life.

But the wait list for Medicaid waivers is daunting. Although 11,000 North Carolinians with I/DD have a waiver another 12,000 are waiting. And many who could apply aren't even aware waivers exist. In fact the scale of potential need is much larger—the NC Council on Developmental Disabilities estimates there are 185,000 children and adults with I/DD in the state. Meanwhile, only 250 more waiver slots were opened up for 2017.

The housing gap is just as large. Those with I/DD must compete with the poor, seniors, homeless, mentally ill, and substance abusers for scarce affordable housing. Only those families who are wealthy enough can afford to buy homes for their adult child with I/DD. Some adults with I/DD can work, often with the help of job supports, but even then few will be able to achieve economic independence.

Meanwhile there are four trends affecting the housing shortage. Two are demographic. The first is that the I/DD population is living longer, thanks to medical advancements, and thus outliving their parents. Second is that the I/DD population is growing, not plateauing. Orange County's school systems are adding about 100 new significantly disabled young adults to the community each year, and UNC's expertise in autism is attracting desperate families from across the country and world.

Two other trends are regulatory. The first is HUD's redoubling of its efforts to de-institutionalize and desegregate special needs populations. This may work well for some populations, such as the mentally ill, and for high functioning adults with I/DD who can blend into independent living with minimal supports, but the more severely affected adults may not fit this idyllic model. Moreover, not all adults with I/DD want to blend into a typical community. Many thrive in communities of intentional living... settings where peers congregate and have an easier time making friends and receiving support services.

The second trend is with HUD's Section 811 funds. Instead of providing incentives to create disability housing, it now only provides funds for portable housing vouchers. The administering agency, the NC Housing Finance Agency, refuses to seek Section 811 funds because of added costs and concerns that developers will not make commitments for disability housing if there is no way to guarantee the vouchers will be spent in their developments. Any future Section 811 funds will be left on the table unless there are changes.

TALKING POINTS

- The trends found in PACID's member survey probably reflect similar conditions in every county. (PACID is local, not statewide.)
- At best, only half of those that have applied for a Medicaid waiver have one. These are crucial for connecting isolated adults to jobs and the wider community.
- Our adult children live with aging parents, largely "invisible" to the affordable housing system.
- Affordable and quality housing options are very scarce, and I/DD adults are competing with groups that have recently had a higher profile, such as the mentally ill.
- The Supported Living feature of the Medicaid waiver is new and intended to be widely used by 2019. Supported Living, which features two roommates with an overnight care provider, may become one of the best housing options for I/DD adults.
- However, the regulatory push to desegregate special populations is not beneficial for the entire I/DD population. Some adults benefit from clustering for social purposes, and others need a higher level of staff support.
- Ultimately, housing and Medicaid waivers are intertwined, each necessary for the other to be successful.

WHAT PACID WOULD LIKE TO SEE

1. Extend to 5 years the 3-year Medicaid waiver re-evaluation for the adult I/DD population. The reviews are expensive and time-consuming, paid for under the waiver, and resulting in little or no new information. This might free up funds to increase waiver slots.
2. Increase the number of Innovation Waiver slots to reduce the wait list. While 11,000 children and adults currently have a Medicaid waiver, the wait list stands at 12,000. People should also know where they stand on the wait list.
3. Restore the cuts in single stream funding to MCOs.
4. Not everyone who qualifies for a waiver knows it even exists. Schools and doctors should be talking with parents about them.
5. Endorse a wide range of residential options.
 - a. Facilitate quality group homes. First, allow new ICF beds. Second, enable financial soundness of 4-bed group homes by increasing reimbursement rates. (New regulations require 4-bed versus 6-bed homes, but staffing demands are not proportionately diminished.)
 - b. Expedite the rollout of the Supported Living feature of the Innovations Waiver. First, charge NCCDD with administering a second demonstration project, complementary to the one being carried out by Vaya. Second, research the creation of a roommate match-making clearinghouse.
 - c. Support a demonstration project for “intentional community” living, with assurance that their waivers would not be jeopardized. One approach would be to piggyback on large new mix-use developments to reserve 5-10% of the affordable housing units for people with I/DD. Backed by NC Housing Finance Agency incentives, a developer could work with an organization to manage referrals. Another approach would be to fund a feasibility study for a full-fledged “intentional community”, modeled after others across the country.
 - d. Fund a step-down unit at Murdoch to allow for more effective treatment as well as faster turnover, with people going to an intermediate level of supervision before being discharged into the community.
 - e. Support development of a community infrastructure for housing by providing \$20 million to NC HFA’s NC Housing Trust Fund. (per NC Housing Coalition)