

**Comment:**

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A Matter of Perspective: Looking forward to Our Place

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Phil Desmond recalls a terrifying thought a year ago, when the COVID-19 pandemic had just begun its march across the county: "I remember feeling so emotional talking to Jan, thinking ? what if we were taken by COVID-19 today?" Rather than an existential fear for himself and his wife, Janette, the focus of Desmond's alarm was what would happen to their son, Dan, who was diagnosed with autism at the age of 2. Now 29, Dan lives with his parents in Portsmouth, one of the more than 762,000 people with intellectual-developmental disabilities (IDD) living in the home of a family member and receiving long-term supports and services (LTSS). The number represents more than 60 percent of the total

who received Medicaid or state-funded LTSS. That's according to the most recent estimates from the Residential Information Systems Project (RISP) in 2017.

Dan Desmond's funding and the coordination for his services comes through Portsmouth-based One Sky Community Services, one of 10 nonprofit area agencies in New Hampshire contracted with the state to provide access to and coordination of a range of developmental services and supports for individuals with IDD and acquired brain disorders. But it is home where Dan's parents remain his self-described "anchors." Complicating Dan's autism diagnosis is a seizure disorder. He's perfectly capable of taking the prescribed medication ? in fact, Dan is independent in many ways, from cooking to cleaning and laundry, but his parents assure that the supports he needs to be independent and safe are in place. Phil describes a time very recently when he picked Dan up from his job at Port City Pretzel and Dan showed him an email that he didn't quite understand, but that he was happy to reply

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**Dan Desmond, right, was diagnosed with autism at the age of 2. Now 29, Dan lives with his parents, Phil, left, and Janette Desmond in Portsmouth.**

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## Perspective

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to. What Phil saw was a sophisticated scam targeting his son for money. They were able to talk through it but the conversation left Phil with a deeper sense of just how vulnerable his adult son is.

"As independent as he is," Phil said, "there is still a certain vulnerability where it's important to have someone there." Adds Janette, "This has been in our thoughts since Danny was probably in high school, and we started thinking, 'What's going to happen, what's going to happen?' He's perfectly happy living with us. But there's going to be a time when we just can't do this anymore."

That uncertain future is a concern that a growing number of family caregivers are voicing and a future that estimates predict is quietly edging toward a national caregiving crisis. The average age of family caregivers in the U.S. is nearly 50 years. According to AARP, some 34 percent of caregivers are 65 years or older, with other estimates placing as high as 80 percent the portion of caregivers who are at least 50 years of age.

For the Desmonds, the solutions for Dan's future housing and support are slim: group home, adult foster care, an accessory dwelling unit. "We've always tried to look to the future, not just tomorrow but two years, five years, ten years down the road ? when we knew what was out there, which was the group home possibility or an accessory apartment on our own house ? everything that was available sounded horrible because we know Danny. We feel that in a group home setting he would be miserable. He'd be miserable and we'd be miserable."

The Desmonds believe they found a housing model to ensure Dan has a supportive home in the future. But finding a solution and bringing it into being are two steppingstones with a wide gap between them. "The biggest problem," Janette observes, "is that other parents, like us, have a lot on our plates. You talk about it, you're passionate about it; but you're scared, you have no idea where to start."

Casting about to find other, likeminded parents of adult children with IDD, who were seeking answers to the same questions, the Desmonds met up two years ago with Laurie McIntosh and Ron Walton of Dover who were already

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exploring an idea known as Supportive Housing. Along with other area families, they formed an advocacy group known as "Seacoast Area Supportive Housing."

As their network connections grew across the state, with other families and a range of housing officials and stakeholders, the Desmonds were getting a crash course in a complex system of funding, development, and regulation that crisscrosses government agencies and overlaps the lines of public and private efforts. By the time the group was celebrating New Year's 2020 with an open invitation party, it had morphed into "Our Place" and gained its 501c-3 status as a non-profit, along with an abundance of experience and training from others who had successfully taken the path ahead of them. A major guide has been a toolkit made freely available by Visions for Creative Housing Solutions, based in Enfield, N.H.

Home to nearly a dozen adults with IDD, the rural Enfield setting opened in 2014 with a farmhouse ? a one-time inn ? and outbuildings that accommodate individual bedrooms as well as efficiency apartments. The residents are free to come and go according to their own schedules and needs. A number have jobs in town or pursue other activities in the area with their own support staff. Demand for this model of supportive housing among Upper Valley families has already led to Visions growing into Hanover and Lebanon.

Demand for both support and housing is only expected to grow and will likely challenge what the existing system can handle. The current support model is leaning heavily on aging caregivers to provide unreimbursed hours of care.

Between 1998 and 2017, there was a 134 percent increase in the number of people with IDD living in the home of a family member and receiving long-term supports

and services through Medicaid. In 2017, the average Medicaid expenditure for adult services for those 22 years or older was more than \$54,000 per person.

But there is a stark difference in the cost of supporting someone at home and supporting them in any other setting. The average Medicaid expenditure for an adult living at home was just over \$25,000 for the year. In other settings, Medicaid services for the year cost on average more than \$76,000 per person.

The 2017 RISP report asserts, "These differences are due, at least in part, to unreimbursed hours of support provided by family caregivers to family members with IDD living with them?" An AARP report pinned an economic value to those unpaid hours of more than \$400 billion a year. Combine society's reliance on unpaid care with the stark reality of a large caregiving demographic that is aging, and the picture foreshadows a crisis. Indeed, as a recent AARP report observed: "Unpaid caregivers are serving as a core piece of the health and LTSS systems, as well as the main source for long-term care for adults living at home and in the community. Of key concern for policy makers and other stakeholders is whether this arrangement is sustainable?" In a state that prides itself on being institution-free since the closing of Laconia State School in 1991, the idea of housing a group of individuals with disabilities in one setting is not without controversy or opposition. Medicaid, and the policies that it drives in funding support services for people with disabilities, has restrictions on congregate settings, from job sites to housing. But the use of the supportive housing model is growing in other public sectors that are seeking affordable housing for vulnerable populations, like the homeless or those with substance use disorders, while still providing needed personal supports and community services in areas like job development and health care.

Janette, who has family members with experience running group homes, cites a major difference between the supportive housing model and a group home is a marked increase in independence and choice for residents. "It's a much more independent living situation that is supported," she asserts. "Danny would still do his own thing, but it would be supported. It's exactly the way so many people would choose to live if they had the opportunity."

Indeed, given the choice, she says, "Danny would probably choose to live with people like him. We're just looking for him to have that choice but to also have it be safe. And that's exactly what Our Place is going to be."

Right now, the hot real estate market has put the biggest stumbling block in the path of Our Place in its search for either raw land or an existing building. The group is open to any property that fits the need to be near infrastructure for transportation, jobs, recreation, and community life.

The goal is that Our Place becomes a thriving hub for its community, as good neighbors and contributors to local life.

"We hope that people will come to know us as something that is a positive thing for the community," Janette said. "That this is exactly who you want living next door to you."

"Personally, I lost my mother a couple of years ago? she was 93," Phil said. "Then I unexpectedly lost my brother this past year. Our mortality, it was right there, you could touch it. And both Jan and I realized we can't be complacent; we have to move something forward. Otherwise, you will never get it done. You feel vulnerable and that's what we want to make sure that Danny doesn't feel. That he's taken care of and that he's comfortable and happy."

For more information, contact: Our Place, Inc., P.O. Box 65, Dover, N.H. 03821, 603-617-6900, [www.facebook.com/ourplacenh.org](https://www.facebook.com/ourplacenh.org), [www.OurPlaceNH.org](http://www.OurPlaceNH.org).



From left, Dan, Janette, Phil and John Desmond. COURTESY PHOTO