

EMPOWERING PEOPLE with Intellectual Disabilities

Living Communities in Massachusetts

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WITH INTELLECTUAL DISABILITIES

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Program on Empowering People with Intellectual Disabilities

To address the lacunae of access to services that children and young adults with an intellectual disability routinely face, the Harvard FXB Center established the Program on Empowering People with Intellectual Disabilities (PEPID) in June 2015. The program looks specifically at the needs of children, adolescents, and young adults with an intellectual disability, including autism – an approach that characterizes the Center’s work. An interdisciplinary center, Harvard FXB works to protect and promote the rights and wellbeing of children and adolescents in extreme circumstances worldwide. The Center pursues this goal by conducting and supporting research, teaching, advocacy, and capacity building.

Dedication

This report is dedicated to our beloved and visionary colleague at the Harvard FXB Center, Heather Adams, who passed away in August 2016 following a courageous battle with cancer. Heather envisioned and founded PEPID, designed the projects it has undertaken, and provided determined and compassionate leadership to the program since inception, as she did for decades within the field of intellectual disability rights. As a human rights scholar and as a mother of a cherished son with an intellectual disability, Heather’s expertise, knowledge, experience, and commitment to advance the rights of and care for the intellectually disabled guided this work each step of the way. Her work and dedication provide ongoing inspiration to her colleagues at the Center as well as in the field.

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INTRODUCTION

This report explores good practices as exemplified by emerging strategies that provide housing and other services to those with intellectual disabilities. Designed not as a thorough study, but as a small set of grassroots exemplars that can inspire and instruct caregivers, service providers, and policy makers, the report examines three organizations. At their core, Autism Housing Pathways, High Spirit Community Farm, and Specialized Housing, Inc. take a human rights approach to providing critical services tailored to the needs of those with intellectual disabilities.

Key themes emerge from these distinct organizations that we not only identify as good practices, but that also advance the human rights of those with intellectual disabilities, including a high value placed on self-determination, equality, access, participation and inclusion, and dignity. In each case, the elements of placing the individual at the center of care and staffing the organization with mission-driven caregivers (many of whom are parents of disabled children), who are dedicated to the intellectually disabled and expert in working with this population, stand out as critical to success.

The human rights of those with physical and mental disabilities as enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD) center on the guiding principles of integrity and self-determination, non-discrimination, full participation and inclusion in society, equality of opportunity, and accessibility.¹ Adopted by the UN General Assembly in 2006, as of July 2016, the Convention had 160 signatories and 166 parties.² While the United States has yet to ratify the Convention, legislation enacted in the 1970s was expanded upon and enacted through the Americans with Disabilities Act, adopted in 1990, to secure the civil rights of persons with physical and mental disabilities.³

Researchers and practitioners have described intellectual disability and autism as “grand challenges in global mental health.”⁴ The US Centers for Disease Control and Prevention (CDC) found that the sites in its Autism and Developmental Disabilities Monitoring Network identified one in sixty-eight children aged eight (and one in forty-two boys) as diagnosed with autism spectrum disorder in 2012.⁵ According to the CDC, autism is emerging as a public health crisis. The estimated annual costs within the United States for children with autism are between \$11.5B

1 UN Convention on the Rights of Persons with Disabilities (CRPD), A/RES/61/106, December 13, 2006, <http://www.un.org/disabilities/convention/conventionfull.shtml>.

2 UN Treaty Collection, https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en.

3 Americans with Disabilities Act of 1990 (ADA), with changes made by the ADA Amendments Act of 2008 (P.L. 110-325) effective January 1, 2009. See the US Department of Justice website, ADA.gov, for the complete statutes, <https://www.ada.gov/pubs/adastatute08.htm>.

4 See, for example, Nalia Z. Khan et al, “Autism and the Grand Challenges in Global Mental Health,” *Autism Research* 5 (2012), 156–159.

5 Deborah L. Christensen, Jon Baio, Kim Van Naarden Braun, et al., “Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012,” *Morbidity and Mortality Weekly Report Surveillance Summary* 65/SS-3 (2016), 1–23, <http://dx.doi.org/10.15585/mmwr.ss6503a1>; see also CDC, “Key Findings from the ADDM Network: A Snapshot of Autism Spectrum Disorder,” *Community Report on Autism* (2016), <https://www.cdc.gov/features/new-autism-data/community-report-autism-key-findings.pdf>.

and \$60.5B, which includes direct and indirect costs such as special education, medical care, and lost parental activity.⁶ One million children with autism in the United States will become adults in the next ten years. These startling statistics are mirrored throughout most of the world, and new data from the CDC suggest that the estimated number of children identified with autism spectrum disorder may continue to rise.⁷ Under-diagnosis and under-reporting are likely to play a role in the disparity in autism prevalence between developed and developing countries. More strikingly, because of stigma and unsatisfactory medical infrastructure, few autism prevalence studies exist outside of the United States. Furthermore, many regions of the world lack appropriate educational and medical services for children with autism and intellectual disabilities.

An intellectual disability acquired in childhood is in most cases a lifelong condition; gains made through childhood interventions and early supports must therefore be followed through to adolescence and adulthood in order to affect a lifelong, positive influence. Worldwide research related to intellectual disability and autism has focused much of its energies and resources on addressing the needs of young children and not enough on these individuals as they grow into adolescents and young adults. Professor Paul Shattuck and his coauthors in one of the few studies on adolescents have noted that although significant efforts to address the needs of children with intellectual disabilities and autism have been made, "...there has been no effort of a corresponding magnitude to plan for ensuring continuity of supports and services as these children age into adulthood."⁸ Consequently, serious deficits in the planning for adolescence and adult life among this population continue unaddressed. As services all too abruptly cease when a child ages out of eligibility for public sources of support, these highly vulnerable individuals are left unprepared and unsupported to live a dignified and purposeful life.

Against this reality, the need for culturally sensitive, community-based models stands out in relief. In order to fulfill this need, it is first necessary to understand what stakeholders conceptualize as the goal for the individual adult with an intellectual disability. Parents often cite dignity and purpose. How do we arrive at service provision that fulfills this central objective? Are there common threads that transcend culture and geography? In 2011, three self-advocacy groups joined together to define the characteristics they saw as the most important dimensions for community integration of those with intellectual disabilities: physical structure/size (small); rights and self-determination; qualities and attitudes of providers; access to community life; and the meeting of support and access needs.⁹ When

6 A. Lavelle, M.C. Weinstein, J.P. Newhouse, K. Munir, K.A. Kuhlthau, and L.A. Prosser, "Economic Burden of Childhood Autism Spectrum Disorders," *Pediatrics* 133/3 (2014), 520–9, <http://pediatrics.aapublications.org/content/early/2014/02/04/peds.2013-0763>.

7 Christensen et al., "Prevalence and Characteristics of Autism Spectrum Disorder Among Children."

8 Paul T. Shattuck, Mary Wagner, Sarah Narendorf, Paul Sterzing, and Melissa Hensley, "Post High School Service Use Among Young Adults with Autism Spectrum Disorder," *Archives of Pediatrics and Adolescent Medicine* 165/2 (2011), 141–146, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3097532/>.

9 Autistic Self Advocacy (ASAN), Network National Youth Leadership Network, and Self Advocates Becoming Empowered, "Keeping the Promise: Self-Advocates Defining the Meaning of Community Living," 2011, <http://autisticadvocacy.org/home/policy-center/reports-and-brief-materials/keeping-the-promise-self-advocates-defining-the-meaning-of-community-living/>.

these ideas are more definitively understood, service providers and policy makers are better able to translate these concepts into the sustainable provision of services for people with intellectual disabilities.

To meet this challenge, Harvard FXB Center developed this series of case studies. A key objective of this work is to provide a resource tool for parents and caregivers while simultaneously informing policy makers as they respond to the growing need for services for this population. The cases here focus on the transition from childhood to adult services, particularly in the area of housing.

The Autism Housing Pathways case also discusses the lack of basic skill training for those with intellectual disabilities and some of the steps it has taken to address it. Beyond the scope of the current paper, several innovative private organizations are creating solutions in these areas, such as the lack of skill training for independent life. For example, 3LPlace in Somerville MA has developed an extensive curriculum (more than 600 pages) to help with the transition to independent living, which is freely available to other organizations.¹⁰ Specialisterne, an information technology consultancy in Denmark, has actively recruited individuals with Autism Spectrum Disorder to test software, training them in the soft skills necessary for successful employment and modifying the hiring process.¹¹ SAP, the German software company, has partnered with Specialisterne for a neurodiversity hiring program, which includes general work training, specific training on social cues in the workplace, mentors, and team buddies.¹²

Our analyses address the current deficit in evidence-based knowledge on intellectual disability, including autism, and its significance as a component of the increasingly pressing global mental health challenge. In addition, we hope this work will fulfill one of the human rights objectives of the CRPD: to raise awareness of disability and promote cooperation within this field. We aim to contribute to the transformational vision of the CRPD to address the asymmetry of power of those with disabilities so that this population can make the transition from “objects” of pity and charity to “subjects” of rights (rights bearers).

10 3LPlace, *Living, Learning, Linking: The 3LPlace Transition Curriculum* (Somerville, MA: 3LPlace, 2015), <http://www.3lplace.org/tcp.html>.

11 For an overview, see Martha Lagace, “The Surprise Right Fit for Software Testing,” Working Knowledge Blog, Harvard Business School (HBS), April 18, 2008, <http://hbswk.hbs.edu/item/the-surprising-right-fit-for-software-testing>; for greater detail, see the case: Robert D. Austin, Jonathan Wareham, and Xavier Busquet, *Specialisterne: Sense and Details, Case 608-109* (Cambridge, MA: HBS, 2008).

12 For an overview, see Roberta Holland, “Neurodiversity: The Benefits of Recruiting Employees with Cognitive Disabilities,” Working Knowledge blog, HBS, July 11, 2016, <http://hbswk.hbs.edu/item/neurodiversity-the-benefits-of-recruiting-employees-with-cognitive-disabilities>; for greater detail see the case: Gary P. Pisano and Robert D. Austin, *SAP SE: Autism at Work* (Cambridge, MA: HBS, January 19, 2016).

METHODOLOGY

Researchers conducted interviews with key stakeholders (including caregivers, service providers, and civil society) about service delivery organizations in Massachusetts in order to identify those focused on providing community housing for adults with intellectual disabilities, including autism. The three case studies were identified by the author based on recommendations from these key stakeholders and her own experience in this domain. Key Informant (KI) interviews were conducted with leaders of the three living communities selected using a detailed qualitative approach to understanding how the needs of this population have been addressed within each model of care provision. KI interviews were conducted in person wherever possible and via telephone and Skype when an in-person interview was not feasible. The case studies analyze and identify the major barriers facing each model of care provision; document the theory of change for each organization; and assess the implications for future disability care.

The sample is small and highly selective and so the findings are advanced here as a set of rich insights into a range of models with a community housing focus.

Our analysis documents the vision, challenges, hurdles, knowledge, and good practices undertaken to develop each model of care provision. As families, caregivers, and communities — no matter where they are geographically — ultimately shoulder the responsibility of identifying and implementing services for this population, these case studies also highlight ways in which those with this responsibility can be supported, taking into account existing policy, local conditions, cultural norms, and resources.

AUTISM HOUSING PATHWAYS: A CASE STUDY

Since the 1960s, individuals, policy makers, providers, families, and stakeholders have been engaged in discussions about how to provide the best model of care for people with disabilities.¹ Should it be care? Should it be choice? Should it be access?² Stationed at a crossroads at the intersection of these three models, Autism Housing Pathways (AHP) is built on a framework that places “family” at its center. “What is intuitive to families is not intuitive to service providers or state agencies,” explains Catherine Boyle, the organization’s founder.³ As a family organization, AHP is well positioned to understand what information other families may lack and respond accordingly.

Many of the case studies in this report paint a clear picture of organizations that provide housing for adolescents and adults with disabilities. However, in contrast with these organizations, AHP is not a service provider. As Boyle describes, AHP bridges the gap between what is funded by the state, including the necessary documentation that the state requires, and what is needed for people with disabilities to lead a life of dignity. The organization helps families identify or innovate housing plans that work for them and best make use of the available supports. Through group and individual trainings, and other public materials readily available on their website, AHP also plays the role of building the capacity of families and helping them prepare adequately for all financial aspects of adult living for their loved one (including housing development, housing operations, support services, and medical services).

Origins

A group of families whose children were enrolled in Nashoba Learning Group brought about the founding of AHP, a Massachusetts tax-exempt nonprofit corporation. They began meeting in June 2009 to plan a group home for their aging children with autism. However, as many of the parents began to realize, each family’s needs were disparate. Some families believed their loved one would fare best in a community-based apartment or home, while others sought a shared living arrangement (SLA)⁴ or an accessory unit adjoining a relative’s home. Each individual with disabilities also required differing levels of support, some needing 24/7 attention.

Despite each family’s differing needs, the group did not want to disband, as they were beginning to understand the value of learning jointly about housing needs

1 Micaela Connery, “Disability Housing: What’s Happening? What’s Challenging? What’s Needed?” Working Paper (Cambridge, MA: Joint Center for Housing Studies, Harvard University, April 2016), 1, <http://www.jchs.harvard.edu/research/publications/disability-housing>.

2 Ibid.

3 Catherine Boyle (president and founder, Autism Housing Pathways), FXB interview, May 11, 2016.

4 According to the Arizona Developmental Disabilities Planning Council, a shared living arrangement (SLA) is an arrangement in which “an individual, a couple or a family in the community and a person with a disability choose to live together and share life’s experiences.” Arizona Developmental Disabilities Planning Council, *Shared Living: A New Take On An Old Idea* (National Association of State Directors of Developmental Disabilities Services, 2013).

for the Massachusetts autism community and creating the resources to meet these needs. For instance, they could problem-solve around how best to tap into government funding, an inadequate and diminishing source when pitted against the rising population of people with disabilities. “Because we didn’t want everyone reinventing the wheel, we decided to create an umbrella organization,” says Boyle, who was also one of the parents of a child with autism in the Nashoba Learning Group.⁵

In 2010, Autism Housing Pathways was incorporated and became an umbrella organization that addresses the dearth in resources, research, and training on how to provide self-directed housing supports for adults with autism and other developmental disabilities. As mentioned earlier, AHP is not a housing provider; rather, as a clearinghouse that builds the capacity of individuals and their families to prepare for adult living, the organization works against a backdrop where adequate funding supports and housing options are often sparse. As in other states, the housing landscape for persons with disabilities in Massachusetts is a dismal one. As reported in 2015, there are currently 800+ in the “Turning 22 class” in the state living with developmental disabilities, yet the Department of Developmental Services (DDS) can only cover about 200-250 people with 24/7 housing supports when they turn 22.⁶ Overall, this gap means that only 13 percent of current young adults with autism will receive residential supports from DDS when they turn 22.⁷

Do families have the right to speak for their adult children with autism or choose their housing? While this question is fraught within the autism community, AHP operates with the assumption that family members are usually the primary support providers of their adult children with disabilities, and therefore, families must have a seat at the table. While there is a kernel of truth to the myth of caregiver benevolence, individuals with disabilities can often be deliberately and negatively influenced by people who do not have their best interests at heart. “As soon as you put a vulnerable person in the middle of a situation, there is always a chance of abuse or being taking advantage of,” says Boyle.⁸

As a result, AHP takes the stance that multiple people at the table ensure multiple checks and balances. The family-driven approach promotes the well-being of people with disabilities and arms individuals with self-empowerment and self-direction with the backing of adequate familial supports where necessary.

Organizational overview

“Everything we do is a roadshow,” explains Boyle.⁹ The Massachusetts organization’s board is made up of four elected directors, plus the president, who represent a variety of voices and bring manifold perspectives to the table. Each board member’s son or daughter is on a widely different level of the autism spectrum and lives in varied forms of housing. One member of the board is a

5 Boyle interview.

6 Catherine Boyle, “Housing? I’ll think about that tomorrow...,” AHP blog post, May 19, 2015, http://autismhousingpathways.org/raising_the_roof/.

7 See the Autism Housing Pathways website at <http://autismhousingpathways.org/>.

8 Boyle interview.

9 Ibid.

self-advocate (i.e., a person with a disability) and not a parent at all, and one of the parents is also autistic. “I like that balance a great deal,” says Boyle.¹⁰ The myriad perspectives that comprise the board mean that AHP brings forth the voices of individuals with autism and still remains a family organization, guided by the understanding and commitment of parents of people with disabilities. As such, amid the many organizations that advocate for adolescents and adults with disabilities, AHP holds an important stakeholder role in the disability rights movement.

Under Boyle’s direction, AHP is run by volunteers and a handful of paid employees who are funded by grants. Five AHP staff members are trained to administer “person-centered planning,” a transition approach that informs the way AHP works with individuals and families. Rather than having decisions made for them, the person-centered model empowers persons with disabilities to make their own decisions about housing. As AHP states on their website, “While the family is a valuable source for information, even individuals with extreme impairments can provide input about their likes and dislikes.”¹¹

Though the environment of autism politics is often a highly charged one, AHP strategically maintains a neutral stance, oriented only to finding the appropriate transition route for each family’s adult child. Whether a parent is a neurodiversity advocate or a fervent believer in the anti-vaccination movement, AHP assumes that every family is going to need to address the question of housing. At the core of this understanding is the notion that housing provisions for individuals with intellectual and developmental disabilities are unique and best provided for through a person-centered planning method. Through person-centered planning and workshops, AHP starts with the person and his or her needs to problem-solve how they can best be supported in a housing situation that will ensure the best version of themselves.

Currently, Autism Housing Pathways is in a unique stage of growth. As of fall 2015, the founding president has taken on a base salary for the first time. Boyle is also paid by grants for certain projects, and her base pay derives from donations, membership fees, and AHP fundraisers (“Dancing with the Celebrities” is one example). These funding sources also pay for aspects of AHP’s work that are not directly related to grant-funded projects, like their website and some other core administrative costs such as photocopying for workshops and software.

Boyle describes an all too common narrative that parents of children with autism often face. “When your kid is little, until ages 6 or 7, the main goal is to get basic services in place, like educational support services,” she says.¹² While for many, the 6-12 age bracket becomes a kind of honeymoon period—parenting is by no means easy, but adequate services are securely in place at this point—by adolescence, Boyle says, “a kind of power struggle” has often arisen, and thinking

10 Ibid.

11 For more information on person-centered planning, see the AHP website (<http://autismhousingpathways.org/services/person-centered-planning/>) or the Person-Centered Planning Partners website (<http://personcenteredplanning.com/>).

12 Boyle interview.

about what happens at age 22 and beyond is overwhelming to caregivers.¹³ Consequently, somewhere between ages 18 and 22, parents reach a startling epiphany when they realize state services are not a given, as in Massachusetts, where DDS funding for housing supports for people with disabilities falls far short of needs.¹⁴ Therefore, in many cases, a suitable housing solution remains a distant dream, and many adults – hundreds of thousands in Massachusetts and across the US – tread water waiting for housing for years and often decades.

The four core goals guiding the work of AHP change this narrative for many in the state of Massachusetts. Paramount among these goals is AHP's overarching objective to build the capacity of families. To empower families to anticipate a housing plan for their child before he or she turns 22, AHP disseminates several reader-friendly public materials and hosts interactive workshops. New parents to AHP are initiated with a "Turning 18 Checklist" and a two-hour presentation called "Thinking about Housing." Families can also make use of AHP's interactive web-based questionnaire, "My Benefits Generator," which helps them determine the MassHealth disability supports for which they may be eligible. About four times a year, AHP hosts a day-long workshop that educates families about preparing for their child's transition into adult housing, and about two to three times per year, the organization leads clinics devoted exclusively to applying for a Section 8 Voucher. Though the affordable housing voucher is critical for most family-driven housing structures to work financially, its complicated nature often leaves families frozen in their tracks. But, as Boyle warns, "If you want your kid out of the house by age 30, they need to be on the waiting list by age 18. I meet families all the time who say, 'gee, my kid is 32 and is still not getting a residential placement from DDS; do you think they should apply for Section 8?'"¹⁵

AHP is not just a clearinghouse. The organization also systematically addresses the dearth of evidence-based knowledge on housing for individuals with autism and other disabilities by advancing rigorous research and disseminating findings back to stakeholders with influence. Most recently, Boyle and her team worked with Senator Barbara L'Italien on a bill (originally S 708, now S 2202) that would allow family members to take out a loan to add an accessory apartment of up to two bedrooms in their home.

L'Italien's bill would be instrumental in allowing people with disabilities of varying socioeconomic statuses (as well as the elderly population) to lead lives of dignity and respect. Funding to build an accessory unit would create space for the individual with a disability to live in an annex attached to their family's home, allowing parents to keep in close touch and provide respite without the need for constant vigilance. At the same time, the adult individual would retain ample liberty to live independently. This housing model empowers individuals to stay in the community and live autonomously, all while receiving the support of their family. The alternatives are difficult to swallow. In the absence of a loan, most middle-income families cannot pay 1500-2000 dollars out of pocket per month. "What

13 Ibid.

14 Boyle, "Housing? I'll think about that tomorrow..." <http://autismhousingpathways.org/author/wpengine/>.

15 Boyle interview.

you've done," says Boyle, "is provided an opportunity for the family to be involved without burning out and before an emergency."¹⁶

The key to enabling this system is also contingent upon zoning reform, another recent advocacy initiative taken up by AHP. Many communities uphold very stringent zoning rules as it relates to the construction of accessory apartments or simply do not permit them. With the help of a handful of paid employees and a crew of volunteers, AHP engages with the autism community to advocate for these reforms. As the autism community is large, politically active, and vociferous, AHP is able to gain momentum within the space of minutes through traditional and non-traditional media – 6 or 7 listservs, Yahoo groups, and several Facebook groups, for example. These advocacy initiatives target individuals and families, stakeholders, and the general public. To advance the community's agenda where housing is concerned, AHP regularly mobilizes advocates to send emails, write letters, submit testimonies, and attend hearings. AHP understands its research and advocacy work as a vital contribution that adds to the body of literature on housing design and delivery for persons with disabilities.

But capacity building and research are just two components of many that make up AHP's work. Boyle also reflected on the increasing need to improve the quality of support staff for individuals with disabilities.¹⁷ Currently, support providers of adults with disabilities need only have a GED, driver's license, and clean criminal record check. Once hired, support staff is often provided with the bare minimum for training. Furthermore, the state does not require them to receive training in disabilities, nor do agencies receive Medicaid funds for providing such training. To address this state-wide shortcoming, AHP creates educational tools to advance the caliber of Massachusetts direct support staff. To name just one example, in 2013, AHP released "Learning about reinforcement," a training video that was made available publicly and which was quickly taken up by a major service provider for all new hires in its autism specialty houses. AHP is also beginning to play a role in fostering the relationship between the housing sector and persons with autism, an innovative solution designed to address the many instances individuals with autism are evicted from their homes. It is not uncommon, for example, for individuals with autism to find themselves in housing court upon eviction, an alarming scenario in which they are ill-equipped and underrepresented. To solve what is an access barrier, AHP hopes to improve the capacity of the housing sector to meet the residential needs of individuals with autism.

Challenges

The ambitious work of AHP inevitably has faced challenges. Paramount among these challenges is encouraging parents to think proactively about their child's transition into adulthood. Often parents do not start knocking on the door of AHP until their adult child is 26 or 27 years of age, which is already too late to save enough money to make a down payment on a potential housing option. Unbeknown to many families, saving funds needs to start when their child is at a young age and with the same level of gusto and prioritization that may have

16 Ibid.

17 Ibid.

accompanied their earlier efforts to save for their own college education. Many parents, however, are too busy setting up adequate support services for their family member's immediate needs and wind up scraping together a haphazard plan only when their adolescent is rapidly approaching 22, the birthday that signifies their departure from the public education system and entry into, as one paper has named it, "the challenging and underfunded world of adult service."¹⁸ While AHP continues to get the word out through various media and by word of mouth, the organization still wrestles with increasing its outreach to extend this alert message to all or most families in the state.

According to AHP, the school system could also do better to prepare children and adolescents with autism for adulthood. Though legally education should play a crucial role in impacting the ability of students to be post-secondary and career ready, public schools in Massachusetts often do not adequately prepare their students with intellectual and developmental disabilities for the post-22 environment. School systems need to be better positioned to inform families about what happens after their child turns 22 and teach their students independent daily living skills. These tools will enable these future adults, whether college bound or needing 24/7 supports, to "live as independently as they [are] capable of doing."¹⁹

AHP also recognizes that its outreach does not extend to all communities in Massachusetts. In some cultures, autism is severely stigmatized, and therefore access to services for these families and their children is either cut off or limited. To address what is largely a cultural barrier, AHP has translated several of its educational materials (for example, the "Turning 18 Checklist" and a handful of webinars) into a handful of languages, including Spanish, Vietnamese, and Chinese. (At the time of this writing, Haitian/Creole and Portuguese were next on this translation list.)

Finally, achieving support through adequate funding is a continuous challenge. Noting that the organization is in a transitional phase of growth, the president suggests that increasing AHP's cash flow will be imperative in maintaining its sustainability. Currently, a third of AHP's funding comes from fundraising, individual donations, and memberships, and two-thirds come from grants. In order to increase cash flow, AHP plans to hire a professional fundraising consultant in 2016 to develop a comprehensive fundraising plan. This new model will give Boyle more time to do some of the programmatic work, and it will also generate more funding to do the work itself. An accountant has taken over as treasurer, giving her even more time to invest in programs. The outcome of this intermediate growth phase will help determine how sustainable AHP is in the long term.

Conclusion

When asked about her aspirations for AHP's future, Boyle lists a litany of goals. She wants to develop some in-person trainings and web-based training for

18 Connery, "Disability Housing: What's Happening?"

19 Catherine Boyle, "Independent Living Skills, the Horse that Pulls the Housing Cart," AHP blog post, June 30, 2015, <http://autismhousingpathways.org/independent-living-skills-the-horse-that-pulls-the-housing-cart/>.

persons with autism on how to be tenants. She also aspires to create specific trainings for property managers, public housing authority directors, and maintenance people on how to interact with tenants who have autism. Her team has developed two training videos for direct support staff, but she wants to develop two more; and in an ideal world, AHP's materials will be translated into several more languages. In the long term, Autism Housing Pathways would like to facilitate 50 individuals and their families per year to develop a housing strategy and set them on the path to achieving it.

In the meantime, Autism Housing Pathways can serve as a successful blueprint that addresses a lacuna in the provision of person-centered housing that is both self-directed and family-driven. AHP demonstrates that in the realm of housing for adults with disabilities, much is needed in the form of research, advocacy, and capacity building that goes beyond mere service delivery. For instance, a Section 8 Voucher is the most important government subsidy for people with disabilities, but many families do not know this fact and apply when it is far too late. By empowering families to plan the transition of their child into adulthood with all the right resources, AHP has become a vital tool for the autism community in Massachusetts. This model would do well to be implemented in other states throughout the nation.

HIGH SPIRIT COMMUNITY FARM: A CASE STUDY

High Spirit Community Farm (HSCF), a therapeutic residential and land-based work program for adults with intellectual disabilities, is located in Great Barrington, a bucolic municipality in the Berkshires of Massachusetts, populated by many other life-sharing communities for persons with disabilities. HSCF offers parents an alternative model to institutional care provision and provides a long-term housing solution for people aged 22 and older. At High Spirit Community Farm, residents also become permanent members of the larger Great Barrington community.

Origins

The HSCF philosophy and model of care is based on the Camphill intentional community movement, which began in Scotland in the early 1940s as a blueprint to provide for the needs of individuals with developmental disabilities through community living. The Camphill model derives from the teaching of Rudolf Steiner, who conceptualized people with disabilities as individuals in need of a supportive, community-based housing.¹ Steiner's philosophy, known as anthroposophy, or "wisdom of the human being," takes a holistic view of human beings as connected, spiritually and bodily. Anthroposophy is the underpinning of Waldorf Schools as well as the Camphill movement.² It considers every disabled person as a fully integrated mature individual.

In education, the Camphill approach takes the form of curative education, where art is used as a medium to explore the individual holistically and bring the body, soul, and spirit into balance. In the housing context, which is the focus of this case study, the Camphill model advances the notion of the "intentional community," where people supporting individuals with disabilities are motivated by a drive to empower and uncover hidden potential rather than by monetary incentives. As a result, HSCF, like other Camphill communities, provides staff workers only with non-salaried support in the form of housing, food, transportation, and a small stipend. The provision of intentional care is conceptualized as a service rather than as institutional shift work.

There are approximately 13 Camphill communities in North America and over 100 communities worldwide. Camphill communities within the US provide services to everyone from children to the elderly and are tailored based on the age group they serve. A long-standing US community is the Camphill Special School, located in Glenmoore, Pennsylvania. Visits to Camphill communities around the world contributed to the early development of the Camphill Special School, which is inclusive of the Transition Program at Beaver Farm, a program for 18-21 year olds with developmental disabilities who have already completed high school. The transition program employs a therapeutic component, which caters specifically to

1 Steiner Education Australia website, <http://www.steinereducation.edu.au/steiner-education/curative-education/>.

2 "About," Anthroposophical Society in America website, <http://www.anthroposophy.org/about/>, 2016.

the needs of young people transitioning into adulthood. Since traditional academic work is generally not practicable for these individuals, the focus is directed toward vocational and life skills. All of the work takes place in the context of intentional, residential communities, where many staff and students share a life and a home 24 hours a day. This context creates a rich social and emotional nexus for both residents and staff.

Guy Alma, director of development for the Camphill Special School, has been intimately involved in the concept and growth of the Transition Program at Beaver Farm. He also shares his life and home at Beaver Farm with his wife and the young adult residents. Viewing the Transition Program at Beaver Farm as a prototype for families that are actively seeking to set up other communities where the connectivity between co-workers (known in other contexts as “staff”) tend to thrive, Alma recognizes the need to assist other start-up organizations with expertise. He points to the power of prototypes to enable their replication: “A mission statement is not enough. You need a star and passion that you are following that is recognized by all. This is the only way to stay true and if this is lacking, you are likely to forget why you are there and veer towards living with orthodoxy and begin to make decisions that don’t make sense.”³

One such start up Alma has assisted is High Spirit Community Farm (HSCF). HSCF brings individuals with disabilities into the community at large by providing alternative blueprints to prevailing models in Massachusetts, where institutional care has evolved from hospitalization to smaller group homes and foster care. HSCF is unusual in the state because it provides community integrative services which do not widely exist for young adults with intellectual disabilities. For instance, government housing for people with disabilities can support only about 5 percent of the population, leaving very few viable options for the majority.⁴ HSCF serves in Massachusetts as a prototype for this Camphill model of care, community, and service for young adults.

Organizational overview

HSCF was founded in 2004 by a group of families. These founding families engaged a facilitator, hired an inn in western Massachusetts, and invited as many leaders from the other Camphill communities as could attend. Over three days, the groups went through clip charts, discussed various models, and engaged on how to apply them. Out of this exercise, High Spirit Community Farm was born, based on the Camphill principles of inclusion and community.⁵ HSCF current staff consists of two house leaders, an administrator, and three one-year volunteer co-workers. The board of directors is governed by eight individuals, including Robert Swain and his wife, Ginny Swain, parents of a resident of HSCF. HSCF is structured as a nonprofit 501(c)(3) organization. As a family-driven enterprise, the organization runs on the basis of consensus, intentionally without a designated leader or decision maker.

3 Guy Alma (director of development, Camphill Special School), FXB interview, Spring 2016.

4 Robin Dahlberg, “Finding a Home for Bar,” video, 2012, <http://www.highspirit.org/#!/history/csgz>.

5 Robert Swain (president, High Spirit Community Farm), FXB interview, Spring 2016.

Within the HSCF environment, adults with disabilities live and work together with their caregivers in a supportive family environment, integrated into every aspect of household life and actively participating in the care of the community's farm. As Swain, president of High Spirit Community Farm, explains, "All household members are afforded an opportunity to learn from each other and develop a sense of belonging, purpose and accomplishment."⁶ The organization opened its first house, Seekonk House, in 2008, and a second, adjacent house is set to open in 2016.

Staff members employed by HSCF are unusual in their dedication to the "service" aspect of the Camphill movement and are part of what makes the Camphill model work. Staff members – or in Camphill language, "co-workers" – are trained to commit to building a community of people who are interdependent. This commitment means staff members share their lives fully with their clients. "You don't come to work in a shift," says Robin Dahlberg, board member of HSCF. "Life slows down, technology is put to the side, and you do your day together."⁷

At HSCF, life sharing means brushing teeth together, telling stories to one another, and having breakfast as a community in the morning. Co-living is part of the therapy, and with time, residents start to participate in life in a way that may not be possible in an isolated environment. The benefits are often mutual. "People who work at High Spirit get an extraordinary amount out of it," says Dahlberg.⁸

In addition to fostering a shared community, HSCF offers training in independent living skills and a range of vocational training opportunities, arenas often neglected in the public education system.⁹ HSCF directs a land-based work program, offering on the job training in agricultural work and sustainable practices. Young volunteers are trained to provide care to disabled peers, and through this process, develop leadership skills and core values like respect and inclusiveness.

The surrounding community plays a central role in the Camphill model. For instance, when HSCF was beginning to seek out locations, central placement within the community was a prerequisite. Swain noted it was important to avoid geographical isolation and identify an area where the program was welcomed and could become part of the wider community. Meetings with local community providers such as banks, shops, and restaurants were central to gauging this sense of acceptance.¹⁰

Challenges

Community living models like HSCF face common challenges in funding. Dealing with compliance issues often requires layers of administrative staff skilled in navigating specific state bureaucracies. And despite high personnel expenses,

6 Swain interview.

7 Dahlberg video.

8 Ibid.

9 Catherine Boyle, "Independent Living Skills, the Horse that Pulls the Housing Cart," AHP blog post, June 30, 2015, <http://autismhousingpathways.org/independent-living-skills-the-horse-that-pulls-the-housing-cart/>.

10 Swain interview.

maintaining administrative compliance can require a minimum of twenty hours per week per household. Given the costs, Swain said it was imperative for life-sharing communities like HSCF and other Camphill communities in the US to set up long-term relationships with a funding source.¹¹

Legal burdens can also pose large liabilities and need to be anticipated fiscally. Since it is difficult to maintain a 501(c)(3), Swain notes the need to hire a CPA and lawyer. Because individuals with disabilities cannot be paired with untrained co-workers, the behavior of this population poses significant additional vulnerability. Many of the residents are also taking medications, which requires proper oversight. Staff joining the community on a visa can create a legal challenge, especially if the coworker wishes to extend his or her stay. Farm workers or visiting participants, such as other community life-sharers participating in HSCF activities, add another burden to this complicated web. Appropriate and safe use of cars and other forms of transportation pose further legal obstacles.

Research shows that individuals with disabilities need deep social and emotional relationships to enhance their functioning, including face-to-face and daily interaction.¹² Additionally, because people with developmental disabilities are not necessarily communicative, caregivers often need to devote ample time toward understanding an individual in depth. Though well-trained support staff is often the bedrock of specialized residential communities, Swain noted the difficulty of training and retaining such essential staff. There is an enormous shortage of individuals interested in working in the field of disability services. For one, within the US, a sparse number of training programs exist to educate those who conduct the day-to-day work of caring for adults with an intellectual disability. Secondly, those who do engage in this work encounter low pay scales and often lack higher education. Support staff also often lack social security and retirement planning. As a result, over time, caregivers may well face impoverishment.¹³ Swain stressed the need for future models to provide viable compensation packages (including real wages, benefits and social security) to its employees and educate the state and other advocates on the true cost of these services.¹⁴

Conclusion

In recent history, most Massachusetts adults with developmental disabilities were housed in large state institutions.¹⁵ But as the example from HSCF shows, significant progress has been made in reshaping society's understanding of the full extent of rights and capacities of individuals with disabilities, and the range of housing solutions that should be available to them. HSCF, like other residential programs portrayed in this report, represents a shift in disability services that focuses on including this population in communities rather than separating them.

11 Ibid.

12 See Gerald Mahoney and Frida Perales, "Using Relationship-Focused Intervention to Enhance the Social-Emotional Functioning of Young Children with Autism Spectrum Disorders," *Topics in Early Childhood Special Education* 23/2 (Summer 2003), 74-86; Tanis Bryan, Karen Burstein, and Cevriye Ergul, "The Social-Emotional Side of Learning Disabilities: A Science-Based Presentation of the State of the Art," *Learning Disability Quarterly* 27/1 (2004), 45-51; Jane Hubert (ed.), *Madness, Disability, and Social Exclusion: the Archaeology and Anthropology of 'Difference'* (London/New York: Routledge, 2000).

13 Alma interview.

14 Swain interview.

15 Dahlberg video.

However, while the integrative design of HSCF is impressive, thorny questions persist as to how to sustain these models and make them available to everyone. Massachusetts has made strides by replacing institutions for disabled individuals with small group homes. But these homes can only house a small percentage of the Massachusetts population with disabilities, leaving very few options for everyone else.¹⁶ Often community living options can be too expensive for the lower- and middle-classes, and government subsidies can be hard to obtain or are insufficient.

Finding and then equipping staff with the adequate skills is another barrier in creating community models like the one exemplified here. In Massachusetts, adequate training and supports for this type of personnel do not exist.¹⁷ But exemplars like High Spirit Community Farm could be a small part of the solution within the state and throughout the nation. By creating a workforce that is both valued and held to a high standard, organizations inspired by the Camphill philosophy could set a precedent for others.

16 Catherine Boyle, "Housing? I'll think about that tomorrow..." AHP blog post, May 19, 2015, <http://autismhousingpathways.org/author/wpengine/>.

17 Dahlberg video.

SPECIALIZED HOUSING, INCORPORATED: A CASE STUDY

“A voice they never had before”¹ – these words by David Wizansky, the president of Specialized Housing, Inc. (SHI), communicate the drastic shift in the way disability has been conceptualized in the United States. Moving from the past’s complete isolation of people with disabilities in institutionalized settings, or its eugenic view endorsing sterilization, the aim now is to design community-based, independent care settings. Reflecting the change in national consciousness around the topic, traditional advocacy groups have undergone major cultural shifts. One prominent example is the trajectory of the National Association for Retarded Children. From its founding in the 1950s, though “children” was in its name, children did not make up the majority of its constituents. In 1973 the organization changed its name to the National Association for Retarded Citizens, but continued to use the pejorative “retarded” designation until as recently as 1992. In 1992, the association officially became The Arc of the United States, and now according to its website, “the only ‘r-word’ that should be used when referring to people with intellectual and developmental disabilities is ‘Respect.’”² Today, the focus of the disability rights movement is on the individual and his or her autonomous needs. As Specialized Housing recognizes, people with developmental disabilities face a culture that has largely left them behind. SHI’s model of care strives to create a supportive home that “forms a community within the larger community.”³ One resident put it best when she spoke in 2003 at the 20th anniversary of Specialized Housing: “A house is just a building. A home is where you have love. This is my home.”⁴

Origins

Specialized Housing, Inc., (SHI) was started in 1983 in Brookline, MA, by founding members David Wizansky and his wife, Margot Wizansky. As SHI’s website highlights, its mission is “to promote independence through home ownership, work, and active social life and community connections, a community of friends for learning, fun, and growth, and most important, an antidote to the loneliness that adults with disabilities often experience.”⁵

In the early 1980s, Wizansky was working with a social service agency in Brookline focusing largely on child welfare. Within this organization, he set up a staff department for adults with disabilities. As he shifted to looking at residential models for people with intellectual and developmental disabilities, it became apparent that people who were part of this community had no long-term housing.

1 David Wizansky (president and founder, Specialized Housing, Inc.), FXB interview, December 17, 2015.

2 “A History of Name Changes,” <http://www.thearc.org/who-we-are/history/name-change> on The Arc website (2016).

3 David and Margot Wizansky, “The Specialized Housing Community,” <http://specializedhousing.org/content/the-shi-community/>, excerpt on the website from David and Margot Wizansky, *Identity, Self, and the World: Learning From Adults With Developmental Disabilities* (Brookline, MA: Specialized Housing Inc, 2015), “On Community” section.

4 Ibid.

5 “About Us,” <http://specializedhousing.org/content/about-us/>, Specialized Housing, Inc. website (2016).

His agency, however, had set up housing for children at-risk living away from home (not children with disabilities) in a group-home setting. When this house came to market in 1983, the Wizanskys approached a few families of children with disabilities about their needs. The possibility of setting up housing for adults with disabilities entered the conversation, and the Wizanskys ultimately bought the house for this purpose. Over the next 10 months they worked with an architect and developer to make the dwelling more accessible, and this first house has been continuously operational ever since. As of December 2015, Wizanky says, “Only one person has left since 1983 — all the original inhabitants are still present.”⁶ When the couple started Specialized Housing, Inc., they were running operations from their home. In the 33 years since the beginning of this venture, the growth of clients has been driven solely by its reputation. When the Wizanskys first started Specialized Housing, they envisioned a “volunteer-and-leave” model of care, but the number of interested parties kept growing.

Organizational overview

The primary purpose of SHI is to provide families with congregate housing (usually 6 to 10 people with developmental disabilities per household), along with support staff, throughout the week. As with the original house, the model is generally one of a large single-family home or at least a multilevel condo, with common areas and separate bedrooms for each resident, along with a staff office and one or two separate living areas for staff. The first project’s architect, Robert Schafer, described the arrangement in a paper: “From an ownership and management perspective, the home is organized as a condominium.... As a condominium, the house provides a mechanism for the self-perpetuating provision of a living unit and support services.”⁷

Each family buys a share equaling an individual bedroom plus the common areas. The capital costs of buying individual units in the houses are funded by the families of the individuals with disabilities. Families can save money in taxes by claiming the purchase price or mortgage payment on the house as a medical deduction for tax purposes. This arrangement enables people with disabilities to lead a more independent and secure lifestyle in a manner that respects their rights. Residents often get savings from housing that exceeds their family’s initial capital investment.⁸ As the SHI website notes, “Group homes are often subject to changes in landlord or public policy, creating great insecurity for people. Property ownership enhances self-esteem, contributes to individual growth, responsible citizenship, and community involvement.”⁹ SHI serves about 110 individuals with disabilities (ranging in age from 17 to 78, with most residents between 30 and 50 years old). Each condo association has trustees who are generally members of families, and the condo associations generally have an elected executive committee. The budget is allocated in concert with the trustees and the executive committee, and it generally has 25 line items, including fringe benefits, staff, utilities, food, maintenance, and insurance. On average, the per capita cost of

6 Wizanky interview.

7 Robert Schafer, “Supportive Living Environments for the Developmentally Disabled,” Working Paper W98-4 (Cambridge, MA: Joint Center for Housing Studies, Harvard University, September 1998).

8 Wizanky interview.

9 Home page, <http://specializedhousing.org/>, SHI website (2016).

services amounts to 2,000 dollars per month, which covers all staff, food, utilities, and maintenance costs, and allows for a savings account for the individual as well. The funding model for monthly running costs is built on diversified sources, which protects SHI in the event that private funding diminishes. If a family's financial plan were to ever fall apart, public funding would ensure that a resident did not have to leave. This public funding comes in the form of Medicaid, supplemental security income (SSI), and social security. Additionally, Medicaid group adult foster care program pays for care for 34 people (about one third of overall staff costs), and 40 to 50 residents either have a rental subsidy or have access to Section 8 Vouchers for affordable housing. Finally, some residents manage to pay all of their monthly costs from their competitive wages (working in cleaning crews, the maintenance industry, or grocery stores). Due to its diversified funding model, the organization does not rely significantly on any private grant funding.¹⁰

Specialized Housing, Inc., started as a nonprofit but has since become a proprietary sub-chapter S corporation. The reasons for this shift were largely legal, as nonprofit status prevented parents from taking leadership roles in the organization that could potentially create conflicts of interest. Essentially, sub-chapter S status provides income tax exemption as long as the operation is a "small business" and allows the organization to pass on all of the income or losses to shareholders for individual returns. The sub-chapter S structure allows families to have considerable influence. Having families associated with the long-term programming is an integral part of the quality assurance process, according to Wizansky. However, each family has its own set of values with respect to food, sexuality, or other norms; some families desire active and ongoing involvement in the daily life of their disabled family member. A certain level of conflict between vested parties is inevitable in such a context, which is why SHI creates a "manageable entity of the family groups" into committees to mitigate conflict when it arises.

Rather than a formal board of directors, the organization has an advisory board comprising 16 to 18 people, including family members of people with disabilities. This advisory board convenes two to three times a year to talk about high-level issues that concern the organization. SHI's day-to-day operations are managed by a team that includes senior administrative staff and service professionals, who ensure that all aspects of management and maintenance needs are met. In addition, a professional development team, with years of experience working with families and adults with developmental disabilities, reaches out to cities and towns in order to create supportive housing options in these communities. Professional clinicians supervise the staff in each living arrangement, provide support to residents and their families, and liaise with the wider community. The organization takes pride in having a low staff turnover rate — some employees have been a part of the organization for over 25 years.

Live-in staff provides ongoing services, such as overnight and weekend support, in exchange for their housing. Many of these live-in staff are young adults with families, and some are graduate students. There is also a full-time manager in

10 Wizansky interview.

addition to other staff who fill in schedules with the manager to cover hours. Live-in staff members can and often do raise children in these settings. They have their own private space that serves as a permanent residence during their term of service. Live-in staff provide overnight emergency backup. They start their shift at 8 PM, and they go back to their apartments at 10 PM, getting back up in the morning to help clients with breakfast, and any daily routine needs. Another staff person comes in later in the day. All weekend hours have a staff person. Specialized Housing requires residents to be without staff support for a few hours in the morning in order to maintain staff flexibility. As a result, the eligibility criteria for the program examine economic independence and whether the person can manage in a relatively independent environment. People with severe developmental disabilities cannot be accommodated — it is a question of the degree of severity. Most SHI community residents can function somewhat independently with additional support. Many residents work two to three days a week, but some have competitive full-time work. In conversation, Wizansky emphasizes the importance of people being enmeshed in their own community: “All of the sites are within walking distance to the best public transportation available.”¹¹ Houses are located at the edge of a commercial area: in Massachusetts, Specialized Housing has five to six households in Brookline, two in Cambridge, two in Newton, one in Boston, and one in Arlington; in Maine, one in South Portland and another one planned nearby.¹²

Specialized Housing, Inc., currently has about 50 to 60 employees, including about 22 live-in staff and part-time staff. The organization does not rely on any volunteers but does utilize paid relief workers. New recruits undergo parallel training, working with an experienced staff member during the on boarding process. The great majority of employees hold at least a bachelor’s degree, but it is not a requirement for applying. In emergencies, a triple pager system is in place. The manager carries a pager, and the supervisor and administrative staff person (on call) also each carry a pager. The emergency routines are collectively discussed within the housing group so that the individuals with disabilities know how to get help for one another if needed. There have not been any major breakdowns in the system.¹³

An SHI site embedded within a cohousing community offers a particularly interesting example of some of the benefits and challenges inherent in integrating individuals with developmental disabilities, rather than segregating them. Originally brought over from Denmark as a way to promote intentional communities, cohousing environments generally include individual private dwelling units complete with kitchen and bathrooms, combined with an additional common house with a kitchen and other common spaces. People share child care, some meals, some chores, and security. Twenty years ago, over 90 individuals and families moved into a cohousing complex in the Boston area. This grand experiment incorporated many community spaces, including the fireplace, kitchen, and garden area. Among them was a family with children with disabilities. They championed the inclusion of an SHI dwelling in the complex, anticipating

11 Ibid.
12 Ibid.
13 Ibid.

the need for care. Cohousing members were intrigued but cautious. Someone came up with the idea that cohousers were equipped to be “a caring, but not a caregiving community.” The family reassured their fellow cohousers that the care would be provided by Specialized Housing and would not be the responsibility of the community.¹⁴

Specialized Housing manages two units. One houses a staff person, along with his wife and two children. That unit shares a door with the other SHI unit, with room for four adults with developmental disabilities.¹⁵ The cohousing family finds the SHI arrangement ideal for their adult child because the individual can come and go, be more independent, “near us, but not with us.”¹⁶ They also are very pleased with the level of care and experience of the staff. The adult child over time chose when to move into the SHI unit in a gradual process, although the parents started moving in belongings —the transfer of the television set finalized the move.¹⁷

From the cohousing perspective, it “stretches the community.” “It adds a real-world dimension.” “People get to see what developmentally disabled individuals can do.” “It allows the parents to travel.”¹⁸ A tension in cohousing is that the cohousing model is based on every unit participating fully (although not everyone does). The staff family has actively joined in cohousing. The residents in the unit participate in the cohousing community as they are able: they come to pizza potlucks and some group meals, they do some small chores, and they participate in workdays. One individual became very attached to an older cohousing member and mourned when she died, writing a poem about her. One SHI resident is not very expressive socially, but still always stops to pat a cohousing member’s dog. A recent heartbreak for the community was the complete breakdown of one of the SHI residents, who thus needed a different type of placement.¹⁹ With only four individuals housed, this dwelling is much smaller than ten bedrooms, the number SHI considers optimum.²⁰ The smaller size creates some problems for the families involved, since when there is a vacancy, there are fewer people to help carry the costs. Although there is a clause in the SHI agreement that states that families are responsible for paying costs until a replacement is found, this clause is difficult to enforce.²¹

Challenges

The work of managing staff and caring for residents in a life-sharing community can be tremendously rewarding, but there are numerous challenges. Securing a building for housing is the easiest part of this model of care. The difficulty stems from coordinating the staff and the supervisory capabilities and programming. The first problem is identifying workers and training them to ensure that they are

14 Various cohousing members, including the family involved; individual FXB interviews, July 13 and 14, 2016.

15 Wizansky interview.

16 Cohousing member and parent, July 14, 2016.

17 Ibid.

18 Various cohousing members, including the family involved; individual FXB interviews, July 13 and 14, 2016.

19 Ibid.

20 Schafer, “Supportive Living Environments.”

21 Cohousing member and parent, July 14, 2016.

a good fit for the organization and are able to respect the needs of this vulnerable population. Staff expectations, values, communication styles, problem-solving strategies, and roles all have to align with the organization. Since individuals with developmental disabilities have difficulty projecting themselves into the future, they tend to live in the moment, which can pose challenges for staff and require a significant level of patience.²² Secondly, care coordination is a major concern because the managers have to establish and maintain a network of support, ranging from medical care providers to residential staff to advocates. The administration and monitoring of medication is particularly difficult in this context. While the equity-based model focuses on housing, this coordination of support services represents an important part of the work and requires attention to ensure that the patient is given a voice in this process. Finally, in establishing a new model such as this one, getting the geographic location right is essential to its overall success. “Location is crucial to an individual’s growth toward independence and his or her identity as a bona fide citizen of the community,” according to the Wizanskys.²³ Finding the right house in a pleasant and safe neighborhood with good transportation can take significant time and managerial competence.²⁴

The SHI model also requires significant capital contribution from families, so it offers a solution only for those with means. As mentioned in the cohousing example, if someone leaves, the carrying costs can be an additional burden. One parent pointed out that when Specialized Housing began in the 1980s, deinstitutionalization was in full swing—individuals with disabilities had no say in where they went, with few true community-based choices. Now there are more choices, including publicly funded ones — perhaps not enough, but still more, which can make it difficult to recruit replacements that have the degree of independence needed to live in SHI housing.²⁵

Conclusion

In their book, *Identity, Self, and the World*, the Wizanskys suggest that

“The group is an ideal medium for folks with developmental disabilities. People with other disabilities but whose intellect is intact . . . have many methods of expressing their ideas and needs. For those with developmental disabilities, the group can behave as an organism. People are able to support each other in expressing their ideas and needs. Members of a group where trust and safety are priorities feel free to interpret for each other. They can advocate as a group.”²⁶

Specialized Housing creates communities where residents are treated as valuable and integrated members of society and gradually by so doing transforms the community norms surrounding ability and disability. When talking about the

22 David and Margot Wizansky, *Identity, Self, and the World: Learning From Adults With Developmental Disabilities* (Brookline, MA: Specialized Housing Inc, 2015).

23 Ibid.

24 Wizansky interview.

25 Parents of SHI adult child, FXB interview, July 2016.

26 Wizanskys, *Identity, Self, and the World*.

environment that SHI strives to create, the Wizanskys say it best: “At home, they can relax and be themselves ... they can ask for assistance and they can offer assistance to someone else. Home is a community that supports, cherishes, and validates them.”²⁷

27 Ibid.

CONCLUSION

A number of themes emerge from these case studies. And while any theme can be advanced only as an informed observation – given the methods used to identify these cases from within their vast and rapidly changing ecosystem – it can inform the nurturing and rights-based development of new and replicative living communities for the intellectually disabled.

The focus of this report is on Massachusetts' robust efforts to improve housing and social services for individuals with disabilities. The grassroots organizations featured here have come forward over the years to attempt to fill the major gaps between what the increasingly responsive public sector has been able to provide and what the families and professionals perceive as still needed. These organizations were shaped by parents with means, who enlisted others with means and expertise, worked with idealistic and committed young staff, and leveraged every support available from state and national resources. As such, these organizations have worked to define and promote the essential aspects of the best possibilities for young adults (post age 21) with developmental disabilities.

From the perspective of families with a developmentally disabled child, the fear of what will happen when the child ages out of the safety net system (in Massachusetts, at age 22) may haunt them from early days. The preoccupations of dealing with the child's beginning life stages, however, often mean that the post-21 challenges descend upon parents with overwhelming force in the child's teenage years. The scramble for arrangements and funding then intensifies and forces parents and their families to confront the fact that they must devote their entire lives to providing for this one child. In the best of circumstances, the young adult with autism transitions into a loving and self-actualized community, protected by a complex and enduring organization.

From the perspective of overall financial costs, the models of care that seem to offer real elements of dignity and agency and love for young adults with developmental disabilities are proving increasingly expensive. No longer in start-up mode, these organizations must hire and retain personnel who are more skilled in managing the bureaucratic envelope in which they practice. The full-time and part-time staff must be recognized as entering a career they have helped to define—and are now due the full panoply of living wages and full benefits and social security.

From the perspective of the educational system, the efforts of the families and others described in this report highlight the urgency of preparing children with intellectual and developmental disabilities to learn life skills at an early age. Even in Massachusetts, the school system does not adequately teach these children how to navigate the basic social and logistical terrain essential for personal hygiene, communicating and interacting with others, moving safely in various physical and transportation environments, etc. Yet such young adults need to have adopted daily living skills before it is reasonable to think about arranging situations where they might live somewhat independently, find productive work, and fulfill their dreams.

From the perspective of the public health and social services sector, the financial and advocacy efforts of parents and other caregivers serves to supplement insufficient public funds while still requiring ongoing scrutiny and support in terms of oversight and regulation. Yet with the marked increase in projected numbers of young adults with developmental disabilities, it is evident that the public sector is woefully unprepared to meet the financial and protection obligations it must, by law, assume. The time has come to acknowledge the fact that the appropriate protection and care for this increasingly large population of young adults require a strategy that places meeting their needs within the formal health care and social service system of the nation and the state. The challenge has outstripped the heroism of parents with means and the kindness of strangers.

Finally, the health and human rights perspective must raise the egregious issue of disparity. Currently, with regard to young adults with developmental disabilities, the US resembles a developing country, wherein only the wealthy can buy the health care and social services they need. In this country, however, as elsewhere, the great majority of families and of young people with this range of disabilities do not and will not have the financial or social capacity to create for themselves the lives of dignity and self-determination (or voice) exemplified here in these three case studies. These organizations, and the myriad of others not discussed in this report but also working from a core set of values centered in love and protection, have served us all in creating a vision of what might be possible for everyone with a developmental disability who enters the realm of young adulthood in Massachusetts and in the US

But this vision cannot be means tested. Norms and laws in the US and internationally would insist that access to adequate and appropriate care for people with disabilities is a human right, the fulfillment of which triggers an obligation of the state. Obligations framed as rights can be very clear, but if not expressed as supporting a continuum of human needs, they may appear abstract. The case studies described here, however, show in specific circumstances how human rights for all who are rendered vulnerable must attend to basic components of human security—the need for home, community, and a sense of the future. These are human needs, unmet at the expense of great suffering and lost opportunity. We ignore them at the cost of our collective disgrace.

We submit this report on living communities to signal that there exist durable and humane models for securing the rights and capacities of the intellectually disabled. These models take enormous work and devotion to set up and sustain. We honor the pioneers in order to press forward the time when the larger society awakens to the urgency of meeting its obligations to these young people who seek to participate fully in our human community.



The FXB Center for Health and Human Rights at Harvard University is a university-wide interdisciplinary center that conducts rigorous investigation of the most serious threats to the health and wellbeing of children and adolescents globally. We work closely with scholars, students, the international policy community and civil society to engage in ongoing strategic efforts to promote equity and dignity for those oppressed by grave poverty and stigma around the world.

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