INNOVATIVE, FAMILY-DRIVEN HOUSING ARRANGEMENTS

Over the past five years, individuals with developmental disabilities have begun accessing new sources of rental assistance and rental housing, and Medicaid Waiver funded services that offer a wider variety of supports to assist people with living in their own homes.

While there are still lengthy waitlists and limited resources, families are no longer helping individuals get on lists to "wait" for a residential placement. They increasingly want their adult sons and daughters with developmental disabilities to live their own lives in their own homes, and they see opportunities to creatively leverage public and private resources and design customized, integrated, independent housing arrangements.

This website profiles a variety of integrated, independent housing arrangements for individuals with developmental disabilities that families, and in some cases, individuals, have put together themselves. Each arrangement considers these questions:

- What are the individual's unique needs, strengths and preferences?
- What housing assistance and/or services funding does the individual currently receive?
- What housing assistance and/or services funding may be available to this individual in the future?
- What kinds of housing and services are currently available in the community?
- What housing and/or financial resources do the individual and family bring to the table?
- What natural supports and community connections can the individual and family use?

Read these profiles of individuals with developmental disabilities living integrated, independent housing and learn how they and their families resourcefully leveraged housing and supports. It may inspire you to examine the possibilities for your family member.

In what kind of integrated, independent housing environment will your son or daughter thrive? What resources do you have or need? What steps can you take? Use the Housing Planning Chart to sketch how different integrated, independent housing arrangements could work for your family member. Customize each arrangement based on your family member's unique housing and service needs, eligibility for services and housing assistance, and access to housing and support providers.



Integrated, independent housing arrangements enable individuals to rent or own their own homes and choose who lives with them and who supports them, including roommates and caregivers (whether paid providers or unpaid natural supports). Integrated, independent housing also offers tenancy rights and does not make housing contingent upon participation in services. Answering these questions will help you narrow the field of options. There may be several housing arrangements that would make your family member happy, healthy and safe, but if you cannot obtain certain critical housing, service or financial resources, then it does not make sense to pursue this housing arrangement. Likewise, the steps you take to put a housing arrangement in place must be realistic and achievable. Finally, if you are likely to encounter insurmountable challenges or there is no clear, practical path to sustainability, then look at other options.

Regardless, putting ideas down on paper is a great way to begin organizing your thoughts and developing a plan of action. Then, go back and look at the Helpful Links in each profile for more information on various resources, tools and experts. Finally, consult your DBHDS Regional Housing Specialist for assistance with learning about creative housing arrangements and navigating housing resources statewide.



Agency Directed Supports and PERS in a Subsidized Apartment. Ron lives in an apartment property that has units with subsidized rents. He has a Medicaid Developmental Disabilities Family and Individual Supports Waiver which provides personal assistance services and a Personal Emergency Response System. As he ages and his needs change, he will transition from drop-in to live-in personal assistance services. Please click the paragraph above if you want to read more about Ron's journey.



Apartment with State Rental Assistance and Live-in Aide. Ryan is on the waitlist for the Medicaid Developmental Disabilities Waiver. He lives in a privately owned condominium unit. The State Rental Assistance Program (SRAP) provides a subsidy to make the rent affordable. Ryan needs someone to live with him to provide fellowship and monitor his safety and well-being. He received a reasonable accommodation (an exception to the SRAP rules and policies) for a live-in aide and was approved for a subsidy for a two bedroom unit. The aide can live with him at no extra cost. Please click the paragraph above if you want to read more about Ryan's journey.



Consumer Directed Supports, Accessibility & Rent Assistance. Josh lives in an apartment made affordable with a Special Admissions Preference Housing Choice Voucher. A Medicaid Developmental Disabilities Individual and Family Supports Waiver funded environmental modifications to make his home accessible. The waiver also pays for consumer-directed personal assistance, assistive technology, and a personal emergency response system that enable him to enjoy full use of his home. Please click the paragraph above if you want to read more about Josh's journey.



Family Sublease with Resident Assistant. Sean is on the waitlist for a Medicaid Developmental Disabilities Waiver. He lives in a single family home with two friends who also have disabilities and a resident assistant. Sean's dad rents the home from a private owner and then subleases to each of the residents. The resident assistant's rent is reduced in exchange for providing basic supports such as chore reminders, encouragement to attend social activities, and social/emotional "check-ins." Please click the paragraph above if you want to read more about Sean's journey.



Sponsored Residential Services in Independent Housing. Rogan lives in an accessible single family home with his caregiver, Rachel, and her family. Rogan and Rachel both rent from Rogan's parents, Mike and Patty, who purchased the home with a low interest mortgage and placed it in a Special Needs Trust. Rogan and Rachel each have a separate lease. Rogan has a Medicaid Developmental Disabilities Community Living Waiver which funds the sponsored residential services that Rachel provides. Please click the paragraph above if you want to read more about Rogan's journey.

KEY THEMES ACROSS INTEGRATED, INDEPENDENT HOUSING ARRANGEMENTS

Regardless of the approach, individuals and families often shared some similar observations that are worth keeping in mind as you explore new approaches to creating integrated, independent housing arrangements:

1. Start early. Preparing for integrated, independent housing takes a LOT of time and energy, and transitioning from the family home to a new home of one's own does not go smoothly when you are in "crisis mode." Families who successfully transitioned their son or daughter with a disability emphasize that they began planning the move when their child was 20-30 years old. The process often takes several years. This slow, methodical transition enables families to see how the new arrangement functions, to work the kinks out and to make realistic sustainability plans.

2. Build a strong circle of support. Families with strong circles of support relied on these networks to help with many facets of the transition to integrated, independent housing. Some used their network to help find landlords, and others used it to help find caregivers or roommates. Still others accessed their network to help them navigate different systems, including their local public housing agency's Housing Choice Voucher program or to obtain assistive technology and environmental modifications using a Medicaid Waiver for people with developmental disabilities. Some families involved relatives and friends in stocking their loved one's new home full of furniture and household supplies. Do not be shy: this is the time to let people know what you are trying to do and to rally their support for your family!

3. Research the impact of transitioning to integrated, independent housing. When a young adult with a disability moves out of the family home, many government programs and private health care insurers no longer consider the individual a "disabled dependent." Many families did not realize this, and they were surprised by the impacts of this change in status: some negative and some positive. Before you take any serious steps toward transitioning an individual out of the family home to their own housing, check into these issues:

- Health insurance. If the individual has private health insurance, ask whether the individual can retain coverage if he or she moves out of the family home. Some individuals who were covered under their parents' policy as disabled dependents have lost private or military health insurance coverage when they moved out because the health insurer no longer considered them "dependent."
- Supplemental Security Income (SSI). An individual who receives SSI and lives with family does not receive the full SSI benefit if the family does not charge him rent. The monthly SSI benefit is reduced because the family is providing the individual "in-kind support and maintenance" for housing. However, when the individual moves out and pays for housing on his own, the individual may qualify for the full SSI benefit even if he receives rent assistance. Conversely, consider an individual who lives with her family and receives the full SSI benefit. If she moves out and her family provides additional financial support to help her pay the monthly rent for her new apartment, then the individual's monthly SSI benefit could be reduced because her family is providing "in-kind support and maintenance" for housing. Rent subsidies such as Housing Choice Vouchers and the State Rental Assistance Program do not have an impact on SSI benefits. Likewise, ABLE accounts can be used to help pay for housing without impacting SSI benefits.
- Eligibility for other public benefits and programs. Once individuals establish their own households separate and apart from their parents, they may qualify for public benefits such as Supplemental Nutritional Assistance Program (SNAP) or heating and cooling assistance through the Department of Social Services. They may also be eligible for Lifeline, which provides a subsidy for cellphone or Internet service.
- Restrictions on parents as live-in aides. Individuals who employ their parents as personal care attendants through Medicaid Waiver consumer-directed services and rely on them for 24/7 care may encounter barriers to using certain types of rent assistance and employing a parent as a live-in aide. Some rent assistance programs such as the State Rental Assistance Program do not permit applicants to live with parents, grandparents or guardians. Housing Choice Voucher programs may not permit a pre-existing household member to be a live-in aide. If you have questions about potential impacts, contact your DBHDS Regional Housing Specialist.

4. Good caregivers are hard to find. Whether using an agency or directly hiring people to assist individuals in their homes, it is difficult to find and retain knowledgeable, trustworthy, professional caregivers. Caregivers move from one job to another seeking better wages, benefits, hours, commutes and working conditions. If the caregiver's services are funded by Medicaid, it may be hard to offer more competitive pay. For example, Medicaid has strict rules about not supplementing an attendant's rate of pay for hours worked in its consumer-directed Waiver services. Low wage rates make it hard to find and

retain attendants, especially in areas with a high cost of living. Families have found ways to make working conditions more attractive by reimbursing attendants for out of pocket expenses like gas, meals, or entry fees for recreation activities incurred on the job. Other families hire the same attendant privately at a higher rate of pay for *additional hours not covered* by Medicaid consumer-directed waiver services. Some families have helped individuals secure a reasonable accommodation for a live-in aide through rent assistance programs. They offer the attendant free rent in exchange for providing essential care and supports. The attendant is still paid for early morning or evening hours worked and can attend to the individual's safety and well-being during sleeping hours in an emergency.

5. Back up the back up. Parents have learned that naming themselves as Plan B is often not enough in integrated, independent housing: they may be out of town, ill or unable to provide the needed care. It is critical to have a more comprehensive game plan for who will "sub in" if the live-in aide or the visiting caregiver cannot make it because of a weather emergency, illness, sick child, etc. It is also important to know who can serve as a temporary replacement if caregiver turnover becomes an issue. If you currently use consumer-directed services, consider getting to know a few agencies that staff the same service and find out what their capacity is to ramp up supports. Also, get to know other families who have individuals in integrated, independent housing in the community and consider forming a "back-up cooperative" with qualified people who are on call in case someone needs a caregiver to sub in.

6. Be prepared for your role to change. Many parents found that their roles changed dramatically when their adult child with a disability moved into integrated, independent housing. They were no longer "primary caregivers", but they had instead become "care coordinators." The responsibilities include scheduling caregivers, ensuring they arrive on time, monitoring the quality of care, making sure they communicate with the next "shift" as needed, signing timesheets as needed, and enforcing employment agreements. This role can be a difficult adjustment for parents. First, it takes time to help the individual to adjust to a new home and to help the caregivers become familiar with the individual's unique needs, develop a good communication system, establish a routine schedule, and develop some basic protocols. Second, parents sometimes expect caregivers to support individuals the same way they did. One family member noted, "I had to stop assuming the way I prepare oatmeal for my daughter is the ONLY way to make oatmeal!" Third, as individuals began to feel comfortable living in their own places, they would sometimes say during the course of a visit to family, "I am ready to go to my house now." This was a bittersweet moment for many parents, who realized that their son or daughter with a disability had truly left the nest. They could now, in some ways, take the next step in their own lives.

HOUSING PLANNING CHART

Name of Housing Arrangement:

Will This Housing Arrangement Make My Son/Daughter Happy, Healthy and Safe?

What Aspects of This Arrangement Work for Your Family Member?

What Aspects of This Arrangement Would You Change?

What Required Resources, Tools & Experts Do I/My Child Already Have for This Housing Arrangement?

Service-Related Resources

Housing-Related Resources

Experts

Other Resources

What Required Resources, Tools & Experts Do I/My Child Need to Get for This Housing Arrangement?

Service-Related Resources

Housing-Related Resources

Experts

Other Resources

What Are the Steps We Must Take to Put This Housing Arrangement in Place?
1. 2. 3. 4. 5. 6. 7. 8. 9. 10.
What Challenges/Issues Are We Likely to Encounter?
<u>Challenges/Issues:</u> <u>How Will We Address These Challenges/Issues?</u>
What Steps Must We Take to Make This Housing Arrangement Sustainable?
1. 2. 3. 4. 5. 6. 7. 8. 9. 10.

Agency Directed Supports and PERS in a Subsidized Apartment

SUMMARY OF KEY ELEMENTS Type of Housing: Privately managed Rural Development (RD) 515 apartment property Type of Services: Personal Emergency Response System (PERS) and Personal Assistance Services

What Funds the Housing: project based rent subsidy available in some RD 515 properties What Funds the Services: Medicaid Developmental Disabilities Family and Individual Supports Waiver

Meet Ron:

Ron lived in a single family home with his parents until his dad passed away. The old home was challenging for Ron's mom to negotiate with his accessibility needs. Together they moved to a nearby apartment in Warrenton using a Housing Choice Voucher. The unit was fully accessible.

After Ron's mom died, he stayed in the apartment because it felt like home. Without mom, managing consumer directed services became overwhelming, so Ron's case manager helped him move to agency directed personal assistance services (PAS). Recently, the apartment property stopped accepting vouchers and became a Rural Development 515



property with rent-subsidized units. Ron's rent contribution remained the same, but if he moves, his rent amount could increase above what he can afford on his monthly Social Security payment. Ron has also made friends in the complex and has family nearby. These factors influenced his decision to stay.



Ron's case manager helped him access a Personal Emergency Response System (PERS) through the Medicaid Waiver. This system permits Ron to push a button when he is alone, calls 911 for him, and provides a profile including his name, location, and needs. PERS helps him feel safe: he has used it many times for medical or other crises.

Ron's health needs are becoming more complex, so he is going to have the PAS agency start providing a live-in aide for some overnight hours. Ron is open to other arrangements as he

ages, but his team wants to support Ron's choice to stay where he is. As his needs change, his case manager finds ways to get him what he needs.

Ron attends a local day program that even offers him support for occasional evening events. At home, he watches the Washington Redskins, reads books, watches game shows, and listens to his police scanner. Ron shares his thoughts through a Waiver-funded communication device. He says the best thing about his housing situation is, "I get to live independently and do the things I like to do… but that's because I have the right people around me."

The Process, Start to Finish

Here are the steps Ron and his Team took to get his Agency Directed Services and PERS in an Apartment in place:

- 1. Secure a support team of people who care about the needs of the person with a disability and truly want them to be successful. The people on the team may change over time, which is fine. Ron found a case manager, friends and service providers who listen to what he wants and support him to achieve his goals.
- 2. Identify the supports the individual will need to stay safe and independent in housing and follow the rules of the lease, and scope out how these supports will be provided. Some supports may be provided by family, friends and community members, or privately paid caregivers, but other services may be funded by a Medicaid Developmental Disabilities (DD) Waiver or another Waiver. Apply for the appropriate Medicaid Waiver(s) and develop an individual service plan.
- 3. Apply for and use a Housing Choice Voucher to make rent affordable for someone on a fixed income in a high-cost housing market. Local Housing Choice Voucher programs have long waitlists which are often closed. Ask the case manager to make a DBHDS Housing Referral for a Special Admissions Preference Housing Choice Voucher or other rental assistance resource.
- 4. Also apply to rental housing that has project-based rent assistance, such as the Rural Development 515 program. There may be a waitlist for this resource, too. While a person can be on multiple waitlists, a person cannot accept a housing voucher and rent an apartment that has project-based rent assistance.
- 5. Find an apartment near family that is fully accessible, so aging in place is possible.
- 6. Line up caregivers in the home using Medicaid Developmental Disability (DD) Waiver funds by working with the case manager. Personal Assistance Services (PAS) are available in the Medicaid DD Waivers for Family and Independent Supports and for Community Living.
 - a. Determine if consumer- or agency-directed PAS are the best fit. People can use both consumerand agency-directed PAS, or move from one to the other like Ron did.
 - b. Communicate closely with the PAS agency (if using one) on what the person needs and who is and is not a good fit for the position.
- 7. Work with the case manager to secure the PERS system to allow for some monitoring and emergency support options for times when staff or family will not be present.
- 8. Continuously work as a team and reevaluate support needs as people age or otherwise have more complicated needs. While a person's needs may increase over time, respecting their wishes and allowing them the dignity of risk is critical for them to have a good life.

Key Reasons for Success

Ron needed natural supports from his mom to initially find and secure the apartment and the Housing Choice Voucher. He still uses his brother- and sister -in law to help with financial management. Ron's case manager has been with him for many years and is very committed to helping him have the life he wants. The team at Ron's day support program has been with Ron for decades and work really hard to help him with things most people rely on family to do, like assistance with medical appointments. Lastly, Ron and his team work closely with his support agency to find the right personal care attendants and don't settle for people who are not a good fit.

Resources, Tools & Experts Needed

Here are the resources, tools and experts Ron and his team assembled to make this approach work:

Service-Related Resources

- A Medicaid Developmental Disabilities Family and Individual Supports Waiver
- A licensed PAS provider agency to hire, train, pay and manage Ron's personal care attendants
- The PERS monitoring and emergency system so Ron can quickly and easily get help if he has medical concerns or other crises arise
- The team at Ron's day support program who helped him learn about and apply for the DD Waiver, which he received in 2001, and who support him with medical appointments and some after-hours events

Housing-Related Resources

- A Housing Choice Voucher, which Ron and his mom initially used to move into his fully accessible apartment
- Ron's apartment converted to a Rural Development 515 property that offers him a project-based rent subsidy. These properties can have waitlists get on them months or a few years before you plan to move!

Experts

- Ron's brother and sister in law help with Social Security paperwork, visits, and advocating for Ron
- A dedicated case manager helps Ron through any challenges he has

Other Resources

- A communication device funded through the Waiver
- Transportation to and from his day program provided by the County when Logisticare is too unreliable



Challenges/Issues to Be Aware Of

Ron and his case manager readily acknowledge the biggest challenge is finding the right personal attendants. They have worked with a lot of people who were not the right fit for the job, but they stuck with it and communicated clearly with the agency. They did not settle for anyone who did not respect Ron's choices. Starting to use a live in aide has helped with this.

Ron's health has declined significantly in the last decade, which makes it challenging to work and earn more money as he would like. So, Ron works carefully with his Representative Payee (his brother) on budgeting and finding things he likes to do at low or no cost.

Sustainability Plan

Ron is eligible to stay in his apartment as long as he wants with a project-based rent subsidy at this Rural Development 515 property. As he has aged, he has moved from consumer directed to agency directed services, added in PERS for emergency monitoring, uses a communication device more, and is starting to work with a live-in aide. As long as Ron chooses to stay where he is, his team will continue leveraging the Waiver and other tools to ensure his success.

Helpful Links

Housing Opportunities Made Equal of Virginia provides guidance for requesting reasonable accommodations and modifications under the Fair Housing Act, including reasonable accommodations in housing for live-in

aides. See http://homeofva.org/Portals/0/Images/PDF/GuideforReasonableAccomodations.pdf

Medicaid Waivers are a funding source for long term, home and community based services and supports for people with developmental disabilities in Virginia. There are three waivers: Building Independence, Family & Individual Supports, and Community Living. Each funds a different constellation of services and supports. See http://www.mylifemycommunityvirginia.org/

Special Admissions Preference Housing Choice Vouchers is a rent subsidy for people with developmental disabilities in Virginia's Settlement Agreement population. State and local public housing agencies choose to participate and provide a preference in their Housing Choice Voucher and Public Housing programs. See

http://www.dbhds.virginia.gov/library/developmental%20services/housing/set_aside_vouchers_faq_3_2_16.pdf and the DBHDS "My Own Home" Guidebook at

http://www.dbhds.virginia.gov/library/developmental%20services/housing/my%20own%20home%20handbook/dd s_a_home_for_me_final_3_16_17.pdf

PERS is a Waiver funded service that provides a push button alert system to contact emergency services with an updated profile of someone's needs and risks. http://www.dmas.virginia.gov/Content_pgs/ltc-wvr3.aspx

Representative Payees are individuals or organizations appointed by the Social Security Administration to receive the Social Security or Supplemental Security Income benefits for anyone who can't manage or direct the management of his or her benefits. A payee's main duties are to use the benefits to pay for the current and future needs of the beneficiary, and properly save any benefits not needed to meet current needs. A payee must also keep records of expenses and, upon request, provide accountings to SSA of how he or she used or saved the benefits. See https://www.ssa.gov/payee/index.htm

Rural Development 515 Properties are multi-family apartment complexes financed by the U.S. Department of Agriculture. Properties are classified as Elderly or Family and provide unit sizes from studio to 4 bedroom. The USDA also provides project-based rental assistance that is available in some of these properties. Tenants receiving rental assistance pay no more than 30% of their adjusted income for rent. Eligibility is determined by income standards set at the state and county level. To find RD properties in cities and counties in Virginia, see

https://rdmfhrentals.sc.egov.usda.gov/RDMFHRentals/mfhcounties?st_cd=VA&fips=51&name=Virginia

Virginia Housing Search is an on-line search tool for available, affordable rental housing in localities throughout Virginia. The tool has specialized search functions that enable users to find rental housing with accessibility features. See www.virginiahousingsearch.com.

TAGS: accessible, assistive technology, Family and Individual Supports Waiver, housing choice voucher, Medicaid Developmental Disabilities Waivers, personal assistance services, personal emergency response system, project based rent subsidy, rental housing, rural development

Apartment with State Rental Assistance and Live-In Aide

SUMMARY OF KEY ELEMENTS	
Type of Housing: Condo owned by a private	What Funds the Housing: Social Security
landlord	income from individual and reduced rent from
	State Rental Assistance Program (SRAP)
Type of Services: Live-in staff provides	What Funds the Services: A reasonable
fellowship and monitors the person's safety	accommodation allows a live-in aide to live in the
and well-being	unit at no cost as long as he/she provides essential

Meet Ryan:

Ryan lived at home with him mom and sister and attended a private therapeutic day school as a young teen. As his 18th birthday approached, Ryan became interested in moving to his own place. He felt ready to be an adult and have more grown up choices, so his mom helped him explore the options.

Ryan's mom had gone to housing presentations and read about options for Ryan for years, but never found quite the right thing. When she heard about the new State Rental Assistance Program available for people in the DOJ Settlement Agreement population, it sounded perfect, and it would be available when Ryan was turning 18 and ready to move. She realized "I'm not always going to be here. It's my job to get him set up with anything he can receive now."



Since Ryan was still in public school when he was planning to move, they needed to find a new home within the catchment area of his school, which narrowed the search considerably. The family worked with their case manager and the DBHDS regional housing specialist and ultimately found a private landlord who owned a condominium property in Falls Church. The landlord had never heard of State Rental Assistance before, but he had an adult son with autism and was willing to learn more about the program. The landlord agreed to participate and the search for a live-in aide began. The first live-in aide was similar in age to Ryan, but ultimately was not a good fit. While he was able to be home during the necessary overnight hours, he could not offer the peer mentoring and other supports Ryan needed to be successful. Ryan's mom looked within her networks and found a Special Education teacher who was interested in the arrangement and moved in soon after.

Ryan now lives in his own apartment in a beautiful building with security, a balcony, high ceilings, and a giant master bedroom. He is steps from a metro station and can walk to the grocery store and other shops in the area. Ryan is learning that living on his own still means there are rules to follow and responsibilities, but he is proud to have a home to call his own. His mom says he is working on that and "The whole goal is to be really, totally independent one day."

The Process, Start to Finish

Here are the steps Ryan's team took to get his State Rental Assistance apartment with a live-in aide in place:

- 9. Look at various housing options years before it is time to move so the individual and family know what is available and can recognize a great, unique opportunity when it arises. Use this time to prepare a budget and think about where the person may want to live, with whom, what supports the individual will need at home, and how to access critical services (especially if the person is on the DD Waiver waitlist).
- 10. If a live-in aide is a needed support, the team can start tapping its social networks or other places to find a live-in aide. Screen and interview candidates, carefully explain the job, have them meet the person with a disability and talk about move in options.
 - a. Assist the live-in aide with developing a clear schedule of working hours and tasks. If the aide will spend more than 20% of their work time on personal care or support with independent living activities, they must be paid minimum wage for all hours worked in the week. Use private funds if Waiver is not available. Consider whether savings from an Able Account could cover these costs.
 - b. Develop a live-in aide agreement that ensures housing ends if the person is terminated and clearly outlines the parameters of the job. Look at ways to reimburse aides for out-of-pocket expenses related to their work, such as mileage, food, entrance fees to activities, etc.
- **11.** Once the State Rental Assistance Program (SRAP) or another tenant-based rent subsidy is available, ask the case manager to make a referral. If requesting a reasonable accommodation for a live-in aide, the referral must list the name of the live-in aide who will reside with the person.
- 12. When the referral moves forward, complete the application with the local public housing agency. Make sure the individual has a photo I.D., birth certificate, social security card, documentation of income and receipts for all out of pocket medical expenses over the past six-twelve months.
- 13. Upon approval of the rent subsidy, immediately start looking for units and landlords within the area desired and the rent limit set by the program. Explore a private landlord who may own just one property and ask about their willingness to participate in the voucher program.
 - a. Once a unit and landlord are located, determine whether a parent may need to co-sign the lease to lend credit history and accountability.
 - b. Once a unit is located, see what other monthly needs remain—internet, activities, etc. and determine what fits into the budget.
- 14. Apply for Flexible Funding to assist with the cost of new furniture and other moving needs.
- 15. If more items are needed for move-in, use private funds to shop for those items. Don't overbuy. Thrift shops and dollar stores are great alternatives.
- 16. Work with the landlord, DBHDS housing specialist, SRAP program staff, and case manager to coordinate a move in date and move in.

Key Reasons for Success

Ryan's mom was dedicated to looking for options that fit his needs and to letting him move out when he became eligible for SRAP and once supports were in place. She knew a live-in aide would be key to the plan's success and wasn't deterred when the first person did not work out and needed to be terminated. Success also depends on Ryan's cooperation and willingness to assume responsibility for things he may not want to do, which will allow him to gain more independence.

Resources, Tools & Experts Needed

Here are the resources, tools and experts Ryan and his team assembled to make this approach work:

Service-Related Resources

- Even though Ryan doesn't have a Waiver, he is on the waiting list and was able to use interim case management to get help with the move and planning
- Ryan's mom still offers supports and comes by to help or periodically offers the live-in aide a weekend off, and Ryan stays at her house
- Ryan's team decided to use a live-in aide to provide support on nights and weekends when he is not at school

Housing-Related Resources

- Ryan used State Rental Assistance to make rent affordable. He pays 30% of his adjusted monthly income (e.g., Social Security) toward rent and utilities.
- Flexible Funding helped cover the costs of a security deposit and buying furniture for a new apartment

Experts

- Ryan's mom worked closely with the DBHDS Regional Housing Specialist to learn what the housing options were and ensure they followed the SRAP rules
- A dedicated waiting list case manager referred the family for SRAP and Flexible Funds, and located other resources along the way

Other Resources

- A live-in aide agreement that stipulates when the aide must be in the apartment and what tasks the aide does
- Private funds to cover needs outside of Ryan's monthly budget (e.g. new clothing, shoes, household supplies)

Challenges/Issues to Be Aware Of

Ryan's mom found the biggest challenge was finding the right live-in aide. The first person sounded good and the interview went well, but he asked for a lot of time off and kept very different hours than Ryan, so peer support and mentoring did not occur. Ryan's mom advises carefully documenting the aide's performance so if he or she needs to be terminated, you can show cause for doing so.

The next time they sought an aide, the family looked for someone who shared a schedule similar to Ryan's so they would be home, awake, and doing the same things at the same time, such as making dinner. The team learned this was a very serious move and any major lease violation could mean the loss of rental assistance and future opportunities for independence. Ryan's mom and his aide work closely with him to help him understand the rules from the landlord, the property, SRAP, and the aide agreement.

During their housing search, Ryan and his mom learned some apartment properties, known as Tax Credit properties, will not rent to households occupied entirely by full-time students. These properties often accept rent assistance but they have special rules that prohibit a household consisting solely of full-time students from renting a unit. There are some exceptions, notably for households with a member in a vocational training or rehabilitation program. However, this exclusion narrows rental options for young adults with disabilities who are still receiving special education services.

Sustainability Plan

Ryan is very driven to be independent and to keep his rent assistance. As his lease comes up for renewal each year, he will work with him mom to decide if he wants to stay in the current unit or move elsewhere nearby. As live-in aides move on, Ryan's mom will continue to look to her social networks to find new candidates for the job and keep learning from who has been successful in the past.

Helpful Links

ABLEnow is Virginia's Able Account. Families, relatives and friends can contribute to these accounts, and the earnings grow free from federal and state taxes. In addition, there is an annual state income tax deduction of up to \$2,000 per contributor. Generally, the funds in an ABLEnow account are disregarded when determining eligibility for certain means-tested benefits programs, such as Medicaid and Supplemental Security Income. The funds in the account can be used to pay for a range of qualified disability-related expenses for participants. See https://www.able-now.com/

Flexible Funding provides up to \$5,000 in grant assistance to individuals in the Settlement Agreement population to remove barriers that would prevent them from transitioning from less integrated settings to housing they lease or own. Eligible costs that may be reimbursed include security deposits, utility connection fees, furniture, and accessibility modifications not covered by any other source (e.g., Medicaid Waiver). See http://www.dbhds.virginia.gov/library/developmental%20services/housing/flexible%20funding/dds_flexible_funding_fl yer_3_30_17.pdf

Live-In Aides and the Housing Choice Voucher Program is a fact sheet published by the Technical Assistance Collaborative that explains the definition of a live-in aide, provides information about the requirement to allow live-in aides as a reasonable accommodation, and explains how public housing agencies typically review and screen live-in aides. SRAP utilizes a similar live-in aide definition and has similar reasonable accommodation provisions. The live-in aide review and screening procedures that public housing agencies use in their Housing Choice Voucher programs also apply to SRAP. See http://www.tacinc.org/media/13288/Live-in_Aides.pdf

Paying Minimum Wage and Overtime to Home Care Workers is the U.S. Department of Labor's guide for consumers and their families to the Fair Labor Standards Act. It explains when an individual who uses the services of a home care worker (or a family member of an individual who helps manage these services) is responsible for paying minimum wage and/or overtime wages. This is an important read for individuals who engage live-in aides (and their family members who help manage these services), because they may have obligations under the Fair Labor Standards Act. See https://www.dol.gov/whd/homecare/homecare_guide.pdf

State Rental Assistance Program (SRAP) provides rental assistance to individuals with developmental disabilities in the Settlement Agreement population who meet the program eligibility criteria so they have the means to lease private market rental housing that meets their needs. SRAP is available in specific jurisdictions within Virginia where public housing agencies have contracts to administer SRAP funding. For more information about the program and where it is available, see http://www.dbhds.virginia.gov/library/developmental%20services/housing/srap/dds_srapfactsheet_8_19_16.pdf

TAGS: Flexible Funding, live-in aide, natural supports, rental housing, State Rental Assistance Program

Consumer Directed Supports, Accessibility and Rent Assistance

SUMMARY OF KEY ELEMENTS

Type of Housing: Accessible rental housing

Type of Services: Consumer Directed Personal Assistance Services (CD-PAS), Personal Emergency Response System (PERS), Assistive Technology, Environmental Modifications What Funds the Housing: Special Admissions Preference Housing Choice Voucher What Funds the Services: Medicaid Developmental Disabilities Individual and Family Supports Waiver

Meet Josh:

Josh lived in subsidized housing for 21 years. The community was full of friends and support, but Josh had a hard time navigating his home and neighborhood. He wanted to relocate to an apartment in the City of Richmond that would accommodate his active lifestyle. When the Special Admissions Preference Housing Choice Vouchers for the Settlement Agreement population became available, Josh saw a chance to live independently.

Josh remembers the day his aide helped him find his apartment. "When I heard the place was finally mine, my dream came true." Josh did not have family in the area that could help with the move, so he called in some favors from friends. Then, he set about customizing his new home to meet his accessibility needs.



The Family and Independent Supports Waiver funds Josh's services. He receives Consumer Directed Personal Assistance Services daily for three hours in the morning and 10.75 hours in the evening. Josh also has access to a Personal Emergency Response System (PERS) that provides round the clock access to 911 services at the push of a button. He is permitted up to \$5,000 for Assistive Technology and up to \$5,000 in waiver funding for Environmental Modifications each year. Josh has a wheelchair ramp, a proximity wheelchair (that is controlled by his head motions), a communication device in the



form of a tablet that attaches to his chair, and an accessible van. His apartment has also has double electric doors controlled by a remote that Josh has access to and that open with the press of a button. These devices and modifications enable Josh to enjoy full use of his home while reducing his reliance on personal assistance services during the day.

Now Josh is focused "Big Time" on new goals, such as

dating and getting married.

The Process, Start to Finish

Josh took the following steps to put Consumer Directed Supports , Accessibility and Rent Assistance in place for himself:

- 1. Find someone who will be your advocate and barrier buster. Josh had Meredith, his personal care attendant who was by his side, start to finish.
- 2. Learn about the Special Admissions Preference Housing Choice Voucher. Josh found out through word of mouth, but you can ask your DD support coordinator, attend information sessions, or read the DBHDS "My Own Home" Guidebook.
- 3. Ask your support coordinator from the Community Services Board (or a Community Services Board contracted agency) to make a Housing Resource Referral to the Department of Behavioral Health and Developmental Services for the Special Admissions Preference Voucher.
- 4. When your referral is sent to the local public housing agency (PHA), obtain and submit your application for the Housing Choice Voucher program.
- 5. Once your application is approved, the PHA will give you a voucher and several documents for landlords to complete and submit to get a unit approved for the Housing Choice Voucher program.
- 6. Begin the housing search. Josh looked for units that were on the ground level where a ramp could be installed. He relied on Meredith to find these: it took eight months to find a place that would work. Once the apartment property approved Josh's rental application, the PHA inspected the unit to make sure it met basic safety standards. Then, Josh signed his lease.
- 7. Josh made several requests to his landlord for reasonable modifications of his unit. He asked for permission to remove his bedroom door for his wheelchair to fit through, to install an electric door opener system and door knob, and to install a ramp. Josh had the electric doors removed from his old unit and reinstalled at the new unit.
- 8. Josh worked with his support coordinator to request funding from the FIS Waiver for environmental modifications, assistive technology and PERS. Josh coordinates his evaluations with these providers and his support coordinator gets the services authorized and follows up to ensure the services are being provided and meet his needs.
- 9. Josh moved in a few weeks after signing his lease.

Key Reasons for Success

Josh was fortunate to have a personal care attendant who advocated for him and took time to learn about the voucher and other resources to help him be a successful renter. Together they figured out how the voucher works and how to navigate the public housing authority's processes.

Resources, Tools & Experts Needed

Here are the resources, tools and experts Josh assembled to make this approach work:

Service-Related Resources

• The Medicaid Developmental Disabilities Family and Individual Supports Waiver funds home and community-based services such as CD-PAS, PERS, Assistive Technology and Environmental Modifications

Housing-Related Resources

• The Special Admissions Preference Housing Choice Voucher provides rent assistance in the form of a voucher that Josh can take to rental housing providers who are willing to accept it. Josh pays approximately thirty percent of his monthly adjusted income toward rent and utilities and the subsidy pays the difference, up to a maximum allowable amount (based on household size and location). Most Housing Choice Voucher programs have long waitlists that are closed. Public Housing Agencies that offer a Special Admissions Preference provide a preference for the Settlement Agreement population through either (a) a set-aside of housing choice vouchers or (b) a priority on the housing choice voucher waitlist.

Experts

- Virginia's Department of Professional and Occupational Regulation offered information on fair housing rights for Virginians with disabilities, including how to make requests for reasonable accommodations and modifications
- Contractors and therapists provided guidance on home modifications that can increase independence and how to make them

Challenges/Issues to Be Aware Of

During the housing search process, Josh did not know how much rent and utilities his voucher would cover. This made it difficult to find landlords that accept the voucher who have housing within the right price limit. Josh learned it is critical to ask the PHA staff about the maximum rent and utility amount the voucher will cover before you begin your housing search. The PHA process can also be difficult to navigate: make sure you understand it before you begin searching for housing.

One of Josh's biggest ongoing challenges has been to find, hire and keep attendant care providers while living on his own. He relies on personal connections, and has a few friends that are also qualified to be back-up personal care attendants, but turnover of primary attendants remains an issue.

Sustainability Plan

Josh intends to remain in this unit for the foreseeable future and will work on building his social network, his support team, and his pool of back-up attendants. He will continue to look into assistive technology and environmental modifications that can increase his independence in his apartment.

Helpful Links

Department of Professional and Occupational Regulation's Fair Housing Office provides helpful guidance on state and federal Fair Housing laws that apply to people with disabilities. See http://www.dpor.virginia.gov/FairHousing/Housing_People_with_Disabilities/

Flexible Funding is a funding source that is used to remove barriers to transitioning individuals in the Settlement Agreement population to integrated, independent housing and to prevent individuals who have transitioned from jeopardizing their housing stability and risking eviction. See http://www.dbhds.virginia.gov/library/developmental%20services/housing/flexible%20funding/dds_flexible_fundi ng_flyer_3_30_17.pdf

Medicaid Developmental Disability Waivers are a funding source for long term, home and community based services and supports for people with developmental disabilities in Virginia. There are three waivers: Building Independence, Family & Individual Supports, and Community Living. Each funds a different constellation of services and supports. See http://www.mylifemycommunityvirginia.org/

Special Admissions Preference Housing Choice Voucher Program is a rent subsidy for people with developmental disabilities in Virginia's Settlement Agreement population. State and local public housing agencies choose to participate and provide a preference in their Housing Choice Voucher and Public Housing programs. See

http://www.dbhds.virginia.gov/library/developmental%20services/housing/set_aside_vouchers_faq_3_2_16.pdf and the DBHDS "My Own Home" Guidebook at

http://www.dbhds.virginia.gov/library/developmental%20services/housing/my%20own%20home%20handbook/dd s_a_home_for_me_final_3_16_17.pdf

Virginia Housing Development Authority's Rental Unit Modification Program provides grant funding of up to \$10,000 for individuals in the Settlement Agreement population to make accessibility modifications in rental housing. See http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx#.WWZj-f6ovVg

Virginia Housing Search is an on-line search tool for available, affordable rental housing in localities throughout Virginia. The tool has specialized search functions that enable users to find rental housing with accessibility features. See www.virginiahousingsearch.com.

TAGS: accessible, assistive technology, environmental modifications, Family and Individual Supports Waiver, housing choice voucher, Medicaid Developmental Disabilities Waivers, personal assistance services, personal emergency response system, rental housing

Family Sublease with Resident Assistant

SUMMARY OF KEY ELEMENTS	
Type of Housing: Single family home leased by a family and subleased to three individuals and a "resident assistant."	What Funds the Housing: Rental income from the individuals, with assistance from their families
Type of Services: A live-in resident assistant provides socialization, monitoring. A cleaning service cleans the home twice a month.	What Funds the Services: The resident assistant receives reduced rent in exchange for providing these services.

Meet Sean:

Sean Reidt is 24 years old and recently graduated from the George Mason University LIFE (Learning Into Future Environments) Program, a supportive university experience for young adults with developmental disabilities. He is on the Medicaid Developmental Disabilities Waiver waitlist. Initially, Sean was going to move back to his family's home after graduation, but they agreed to pursue another plan to ensure Sean could put what he learned from LIFE into action.

Sean's father, John, consulted a parent in the Fairfax area who had helped several individuals in the LIFE program explore shared housing arrangements. This parent mentor, a mortgage broker, put John in contact with a landlord that was open to leasing his single family home in Fairfax City to John and letting



him sublease it to Sean, two friends and a "resident assistant" who would keep tabs on the residents. In addition, John's mentor connected him to a GMU student who worked in the LIFE program that he believed would make a good resident assistant in Sean's home.

Sean identified two LIFE friends he thought would be good housemates. He and John met with them and their families to pitch the idea and explain how the arrangement would work. They liked the idea! John agreed to sign the lease with the landlord, to pay the rent and utilities, and to pay for a twice monthly cleaning service. John also hired the GMU student as a live-in resident assistant, and negotiated a reduced rent in exchange for performing basic supports such as chore reminders, encouragement to attend social activities, and "checking in" if he observes a health or other concern. John rolled up the rent, utilities, and cleaning service, and divided this equally among all four residents. He subtracted the rent offset given to the resident assistant, divided it by three, and added it to the rents of the three individuals who utilize the support of the resident assistant. Finally, John signed sublease agreements with each renter and the resident assistant.

Sean enjoys his new house: "the best part is having guys to hang out with." He likes walking to Walgreens and the library, and he takes the bus to the student union and the fitness center. When asked about the everyday stuff like cooking and cleaning, he declares "it is super OK with me!"

The Process, Start to Finish

John and Mary Jo took the following steps to put a Family Sublease with a Resident Assistant in place for Sean:

- 1. Consult with a mentor who has experience putting together shared housing arrangements for people with developmental disabilities. Visit other existing shared housing arrangements to see how they were set up and operate. Get a sense of the pros and cons.
- 2. Start identifying people in the individual's circle of friends who might want to move in with him or her. Think about compatibility in terms of schedules, activities, temperament, housekeeping, etc.
- 3. Call each individual and their family member personally and let them know you are exploring a shared housing option. Invite them to come to a group meeting to listen to the proposal and ask questions. Offer to follow up with each one individually.
- 4. Once there are several who agree, bring them together to talk about the process.
 - a. Develop an estimated budget, including expenses for rent, utilities, cleaning service, the rent reduction for the resident assistant, etc. so you can determine what rent to charge each resident to cover these expenses.
 - b. Ask families to help take the lead on or provide support with different activities, such as the housing search, the resident assistant search, or securing a cleaning service. Agree on an acceptable rent range and an acceptable rent reduction range. Make sure everyone understands that the higher the rent is for the lessee, the higher the rent will be for the sub-lessees. The higher the rent reduction is for the assistant, the higher the rent will be for the other sub-lessees.
 - c. Decide which family will take responsibility for signing the lease with the owner and for signing sub-leases with each occupant. The family must be willing to collect rents for subleases from occupants, pay rent on the lease to the owner, send infraction notices to occupants and, in some cases, initiate eviction proceedings if an occupant does not follow the rules of the sub-lease. Moreover, the family must understand that this position exposes their own rent and credit history to some risk. Since John and Mary Jo were the family closest to the home and could most easily monitor the occupants' activities (they live twenty minutes away), John agreed to take on this responsibility.
 - d. Develop a sublease agreement together that spells out what occupants will be responsible for in the home (e.g., taking out trash, mowing the lawn).
- 5. Search for and lease a single family home renting on the market in the agreed upon rent range where the owner permits subleasing.
- 6. Simultaneously, search for and interview potential live-in resident assistants. John advertised on the George Mason University off-campus housing website, in addition networking through his contact in the LIFE program.
- 7. Once the housing is leased and a resident assistant is identified, recalculate the rents using the updated budget numbers, and execute sub-leases with the occupants and resident assistant.
- 8. Map out weekly chores so residents know who is responsible for what chore each week.

Key Reasons for Success

John notes that choice and control are the key ingredients in this arrangement. It is critical to have choice and control over who the roommates and resident assistant are. John wanted to be sure that Sean will be happy with the people with whom he will live.

Likewise, it is critical that families who enter into this arrangement get along well, communicate openly

and offer to support the effort. John notes that, while he has taken a leadership role in terms of signing the lease and paying the bills, the families text and email regularly to check in, make sure things are going smoothly, and ask how they can help.

Another critical component is finding a landlord who will allow subleasing agreements. John notes that he was not ready to make the commitment to purchase a home and lease it. It was important to see whether this kind of arrangement was going to work for Sean, and to see whether he and his housemates really "hit it off." That meant finding a place John could lease and then sublease to the others. Having a relationship with a mentor in the real estate financing field who knows potential landlords was very helpful.

Finally, having the right resident assistant is critical to the success of this arrangement. John notes that they have "lucked out" with finding capable, caring resident assistants.

Resources, Tools & Experts Needed

Here are the resources, tools and experts John and Mary Jo assembled to make this approach work:

Service-Related Resources

- A Resident Assistant who provides basic supports in exchange for a reduced rent
- The local Community Services Board has begun providing Sean three hours of drop-in services, twice per week.

Housing-Related Resources

• A single family home that has a lease that permits sub-leasing

Experts

- A mentor in the real estate field who can advise on leasing and sub-leasing and provide referrals to potential rental opportunities
- A financial planner to examine how to sustain family-funded costs
- A special needs trust attorney

Other Resources

- A resident assistant agreement to attach to the lease that explains the basic expectations of the position (see attached in Appendix 1).
- Financial resources: While Sean's job at Safeway and his SSI benefits generally cover his rent and food expenses, his family covers many of his other costs, such as his cell phone, transportation, medical insurance and out of pocket medical and dental care costs, clothing, haircuts, and recreation. An ABLEnow tax-free savings account could assist with covering these costs.

Challenges/Issues to Be Aware Of

John and Mary Jo found that managing the coverage gap between resident assistants was one of the biggest challenges they faced. Since the families of the other residents were not local, they had to visit more often, especially to keep tabs on housekeeping. The other families also participated by doing more "virtual checks" such as phone calls and using video chats such as Facetime or Skype.

Other issues that caught them off guard were utility costs and appliance failures. Usage is typically higher in shared housing arrangements than in a single family, but it is hard to estimate how much higher. As a result, the first year could involve some financial risk. In addition, the house had several major appliances break in the first year. While the replacement was the landlord's responsibility, it required some "ad hoc" supports from the resident assistant, John and Mary Jo to help the residents adapt their routines while they waited for the installation of their new washer and dishwasher.

Sustainability Plan

Sean has been referred for the State Rental Assistance Program, which will enable him to apply for rent assistance that brings the amount he pays toward rent closer to 30% of his monthly adjusted income. Once Sean knows who his long-term housemates are, John and Mary Jo plan to sell a vacation home they have and do a tax free exchange for the purchase of another home in the Fairfax City area. They will set up a similar arrangement, except as the owner, John will sign leases with each housemate and the resident assistant. John will also begin searching for a longer term resident assistant, since the assistants from George Mason University tend to stay a maximum of one to two years. Eventually, John and Mary Jo will place this home in a special needs trust, and the trustee will be charged with the day to day management of the property, including managing the leases to the housemates and the resident assistant, making repairs to the property, and paying the mortgage and related expenses.

Helpful Links

ABLEnow is Virginia's Able Account. Families, relatives and friends can contribute to these accounts, and the earnings grow free from federal and state taxes. In addition, there is an annual state income tax deduction of up to \$2,000 per contributor. Generally, the funds in an ABLEnow account are disregarded when determining eligibility for certain means-tested benefits programs, such as Medicaid and Supplemental Security Income. The funds in the account can be used to pay for a range of qualified disability-related expenses for participants. See https://www.able-now.com/

George Mason University LIFE Program is an innovative post-secondary program for young adults with intellectual and developmental disabilities who desire a university experience in a supportive academic environment. The program also provides apprenticeships for George Mason University students to gain important experiences and knowledge to work successfully with students with intellectual and developmental disabilities through opportunities such as instructor, resident advisor, internship, practicum, licensure, independent study, field work, mentor, Best Buddy, and volunteer. https://masonlife.gmu.edu/

Special Needs Alliance is a national, non-profit organization dedicated to the practice of disability and public benefits law, including special needs trusts and wills. For a list of attorneys who practice in Virginia, see http://www.specialneedsalliance.org/find-an-attorney. For a list of pooled special needs trusts

in Virginia, see https://www.specialneedsalliance.org/pooled-trust-directory/#virginia. Note: *not all pooled trusts accept real estate.* Verify whether the pooled trust will accept real property before enrolling.

State Rental Assistance Program (SRAP) provides rental assistance to individuals with developmental disabilities in the Settlement Agreement population who meet the program eligibility criteria so they have the means to lease private market rental housing that meets their needs. SRAP is available in specific jurisdictions within Virginia where public housing agencies have contracts to administer SRAP funding. For more information about the program and where it is available, see http://www.dbhds.virginia.gov/library/developmental%20services/housing/srap/dds_srapfactsheet_8_19_16.pdf

VA LegalAid.org has made a model lease available for residential landlords and tenants at http://www.valegalaid.org/resource/model-lease?ref=K5UwY. This lease does NOT contain provisions making a caregiver's occupancy contingent upon employment. Consult an attorney to modify this language and ensure the lease remains in compliance with Virginia Residential Landlord Tenant Act and state and federal fair housing laws.

TAGS: live-in aide, rental income, roommates, shared housing, single family home, State Rental Assistance Program, sub-leasing

4220 Berritt Street has a room being offered at below fair market room rental in exchange for duties as a resident assistant (RA) for the three special needs young adults living in the house. The RA's room is on the lowest level and has a private bathroom. The lowest level has a washer and dryer common area used not only by the other occupants of the house but also by the cleaning lady who comes and cleans every other week.

Below are a list of tasks/duties the RA is asked to complete. The list is not all inclusive but is indicative of the things the parents would like to see for their sons:

• Expected to be at the house every night or notify parents if away and house is without an RA overnight. There is no 'curfew'.

- The position will run from 1 July 2017 30 June 2018.
- Serve as a role model for young professional independent living.

o Hygiene

o Chores/ laundry

o Lunches/ dinner meal plans etc.

- Interact with guys when RA is home and in the common areas...i.e. when preparing/consuming/cleaning up from meals or coming and going.
- Checking to see if they need any assistance...i.e. help with electronics problem, health/not feeling well, directions, etc...let respective parent know if you see something of concern.

• Encourage the guys to go out to social events...activities the RA knows are going on on campus or activities in the alumni community or other places in the local area.

• Checking the mail and reminding Sean to tell his dad the water/electric/gas/other bills have arrived so they get paid

- Get or have one of the guys take the Trash and recycling to the curb
- Outside maintenance
 - RA is not responsible to cut the grass but should remind the guys the grass needs to be cut.
 - RA will assist/direct the guys with shoveling the sidewalk and driveway within 24 hours of inclement weather
- Inside maintenance

o reporting any maintenance issues to John Reidt in a timely manner

o changing the furnace filters and others on a monthly basis or as needed

o blow out the dryer vent in the laundry room (summer months or as often as needed)

o ensuring the housekeeper is performing her job satisfactorily and if not, reporting it to John Reidt immediately

Sponsored Residential Services in Independent Housing

SUMMARY OF KEY ELEMENTS	
Type of Housing: Single family home	What Funds the Housing: Rental income from
purchased by family with a low interest	the individual and the caregiver
mortgage and placed in a Special Needs Trust	
Type of Services: Sponsored residential	What Funds the Services: Medicaid
services caregiver	Developmental Disabilities Community Living
	Waiver

Meet Rogan:

Rogan Gillies lived with his parents, Mike and Patty, until he was thirty years old. Mike recalls Rogan growing bored with their quiet lifestyle: "he pretty much watched movies and stared at the walls when not at his day program or watching airplanes with me." They considered group homes, but worried whether Rogan's needs would be met. "Rogan has limited mobility and communication skills," says Mike, "so he is not a squeaky wheel that gets the grease."

Mike and Patty wanted Rogan to have:

- a forever home,
- a caregiver who supports him to live the life he wants, and
- built-in oversight of that caregiver once they are gone.

They liked the Medicaid Developmental Disability Waiver's

sponsored residential service, in which supports are provided in the home of the person with a disability or the caregiver (the "sponsor"). However, if Rogan were sponsored in a caregiver's home and the caregiver stopped providing care, Rogan would lose both his caregiver and his housing. This double whammy would be traumatic for Rogan, especially if he also had to move away from his community and the relationships he has formed.

So, Mike and Patty decided to purchase and retrofit a single-family home in Fairfax County and rent it to Rogan, his caregiver, Rachel, and her family. As a result, Rogan receives the supports he needs in his own home and maintain connections to his day activities, recreation and social activities, and important people such as doctors and friends. Plus, Rogan's new extended family has widened his social network.

"Now," says Mike, "Rogan doesn't just exist, he lives." His meals reflect those of a younger family, he communicates more, and he lives a more stimulating life than when he lived with mom and dad. On any given day, you will find Rogan in his lounger enjoying the chaos of teenagers listening to loud music, boys playing video games on television, and the dog barking for good measure. Load up the car: it is time for a baseball game!



The Process, Start to Finish

Mike and Patty took the following steps to put Sponsored Residential Services in Independent Housing in place for Rogan:

- 1. Set up a Third Party Special Needs Trust that can accept real estate through an attorney experienced in estate planning for persons with disabilities, a bank or a non-profit organization that has a Special Needs Trust program (see Helpful Links below). The real estate will be placed in the trust after it is purchased.
- 2. Secure a Medicaid Developmental Disabilities Community Living Waiver. This Waiver funds Sponsored Residential Services, which consist of supports that enable individuals to acquire, retain, or improve the self-help, socialization, and adaptive skills necessary to reside successfully in their homes and communities. Individuals can be on the Waiver waitlist for many years. This approach is appropriate for those who have a Community Living Waiver now or are likely to soon (e.g., those are Priority 1 on the waitlist).
- 3. Develop a transition plan for Sponsored Residential Services.
 - a. recruit a caregiver (e.g., network with other families and service providers, use websites that connect caregivers to those in need, and consider single moms). Mike and Patty met Rachel through another caregiver and had used Rachel to provide respite. Rogan seemed to prefer Rachel's lifestyle over some of the older, less active caregivers he had. She is a vibrant single mom who involves Rogan and her children in lots of community activities.
 - b. work with a support coordinator to identify a licensed provider agency for sponsored residential services. Then, partner with the provider agency to hire and train the caregiver.
 - c. if necessary, assist the caregiver with setting aside funds to cover 90 days of operating expenses. Some sponsored residential agencies require caregivers to front this cost as a condition of their employment. It is worth exploring whether agencies that have this requirement can waive or modify it.
 - d. create a step by step plan for the individual to move to the new living arrangement (e.g., start with day visits, then weekend overnights, weekday overnights, and finally permanent residency).
- 4. Get approved for a mortgage to purchase a home for your adult child with a disability. The Federal National Mortgage Association (FNMA), known as Fannie Mae, has special eligibility guidelines for parents who want to buy property for their adult disabled child. It will consider the parent the owner/occupant if the disabled adult child is unable to work or does not have sufficient income to qualify for a mortgage. As a result, the property is classified as a primary residence instead of as an investment property, which means a lower interest rate and a down payment of only 3-5%, instead of the 20-30% a rental property requires. These loans are sometimes called Family Opportunity Mortgages. Ask your lender about this option.
- 5. Purchase and retrofit the home to meet current and anticipated accessibility and support needs. Mike believes almost anyone can live in community housing with the right planning. Since Rogan moved to his "forever home," his mobility, coordination and balance have become more limited, but the house still accommodates all of his needs.
- 6. Amend the Third Party Special Needs Trust documents to place the home in the trust. Identify a Trustee who can manage the real estate when you are no longer able (e.g., collect rents, arrange maintenance and repairs, pay bills, file taxes, etc.). Mike and Patty's sons are the Trustees, but an attorney, bank or a pooled trust program can perform this role.
- 7. Execute separate leases with the caregiver and the individual (see Helpful Links below for a sample

lease).

- a. Rogan's and Rachel's rent covers the principal, interest, real estate taxes and property insurance.
- b. Mike takes the other operating expenses as a passive loss on his income taxes.
- c. The lease requires Rachel (the caregiver) to pay for the utilities and perform the yardwork. The lease also has a clause that makes occupancy contingent upon employment as Rogan's caregiver. If Rachel's employment is terminated, then the lease also terminates.
- 8. Write a contract that clearly defines what acts may result in the caregiver's termination of employment.

Key Reasons for Success

Getting the right caregiver is the key to making Sponsored Residential Services in Independent Housing successful. "The caregiver must be caring, loving and patient – no amount of education or training substitutes for that," notes Mike. In addition, Mike recommends laying careful plans to move from the current to the new housing arrangement, and having a back-up plan in case the sponsored residential caregiver gets sick, needs a vacation, or has a family emergency. Mike and Patty are the back-up for Rachel, and their sons will eventually assume this role.

Resources, Tools & Experts Needed

Here are the resources, tools and experts Mike and Patty assembled to make this approach work:

Service-Related Resources

- Medicaid Developmental Disabilities Community Living Waiver
- A licensed agency to hire, train, pay and manage the Sponsored Residential Services caregiver
- Funds for the caregiver's working capital (amount varies: Mike put \$18,000 in an escrow account)

Housing-Related Resources

- 3-5% downpayment on a single-family home
- Funds for accessibility retrofits, repairs and capital improvements (see Helpful Links for sources of financial aid)
- A house with favorable mortgage terms that meets licensure requirements for sponsored residential services.

Experts

- Attorney familiar with special needs trusts and estate planning
- A mortgage broker familiar with Fannie Mae's Family Opportunity Mortgage guidelines

Other Resources

- A will with a Letter of Intent
- A Third Party Special Needs Trust
- A car for the caregiver to provide the individual safe transportation (negotiable)

Mike did not have these resources but suggests they might be valuable:

- A tool to track trainings the caregiver completes for compliance with the licensed provider agency's requirements
- A financial planner to help run numbers for the home purchase and the home's annual income and expenses

Challenges/Issues to Be Aware Of

Mike's biggest challenge was "letting Rogan go and having confidence in his new caregiver." It was difficult adapting to how Rachel keeps house, prepares food, and dresses Rogan. But Mike admitted, "Rogan was happier and that's what matters." Mike and Patty also faced some unanticipated financial costs: they had to squeeze money from several sources for a new roof and water heater, and to contribute to the caregiver's working capital fund so she could get licensed and begin working. Finally, Mike cautions those seeking a mortgage loan to purchase a home for their child: "Avoid loans with very restrictive prequalification criteria and prepayment penalties."

Sustainability Plan

Rogan's parents are currently his landlord: they collect rent, manage repairs, pay taxes and property insurance and arrange for landscaping. When they can no longer manage this role, they will turn it over to the Trustee for the Special Needs Trust. The licensed provider agency will continue to maintain oversight of Rogan's caregiver.

Helpful Links

Flexible Funding provides up to \$5,000 in grant assistance to individuals in the Settlement Agreement population to remove barriers that would prevent them from transitioning from less integrated settings to housing they lease or own. Eligible costs that may be reimbursed include security deposits, utility connection fees, furniture, and accessibility modifications not covered by any other source (e.g., Medicaid Waiver). See http://www.dbhds.virginia.gov/library/developmental%20services/housing/flexible%20funding/dds_flexible_funding_fl yer_3_30_17.pdf

Livable Homes Tax Credit is a state income tax credit for up to \$5,000 for the purchase/construction of a new accessible residence and up to 50 percent for the cost of retrofitting existing units, not to exceed \$5,000. See http://www.dhcd.virginia.gov/index.php/housing-programs-and-assistance/tax-credit-programs/livable-homes-tax-credit.html

Special Needs Alliance is a national, non-profit organization dedicated to the practice of disability and public benefits law, including special needs trusts and wills. For a list of attorneys who practice in Virginia, see http://www.specialneedsalliance.org/find-an-attorney. For a list of pooled special needs trusts in Virginia, see https://www.specialneedsalliance.org/pooled-trust-directory/#virginia. Note: *not all pooled trusts accept real estate.* Verify whether the pooled trust will accept real property before enrolling.

Sponsored Residential Services: to learn more about sponsored residential services in Virginia, see: http://www.dbhds.virginia.gov/library/developmental%20services/my%20new%20home%20in%20the%20commun ity%20-%20revised%20may%202015.pdf (go to page 8). To search for licensed provider agencies that offer sponsored residential services, see http://ejiujiu0.wixsite.com/providersurvey

VA LegalAid.org has made a model lease available for residential landlords and tenants at http://www.valegalaid.org/resource/model-lease?ref=K5UwY. This lease does NOT contain provisions making a caregiver's occupancy contingent upon employment. Consult an attorney to modify this language and ensure the lease remains in compliance with Virginia Residential Landlord Tenant Act and state and

federal fair housing laws.

Virginia Housing Development Authority's Rental Unit Modification Program provides grant funding of up to \$10,000 for individuals in the Settlement Agreement population to make accessibility modifications in rental housing. See http://www.vhda.com/Renters/Pages/AccessibleRentalHousing.aspx#.WWZj-f6ovVg

TAGS: accessible, Community Living Waiver, family-owned property, Medicaid Developmental Disabilities Waivers, mortgage loan, single family home, special needs trust, sponsored residential services

Next Steps: Identify Options for Your Family Member

We hope these profiles of individuals with developmental disabilities living integrated, independent housing and their families who resourcefully leveraged housing and supports inspire you to examine the possibilities for your family member. These profiles are guides, not recipes, and they represent just a small sample of integrated, independent housing arrangements for individuals with developmental disabilities across Virginia. Families and individuals are continually creating new variations on these arrangements, grafting together elements of different housing arrangements, or conceiving completely new approaches. No two people will follow the same steps and end up with identical housing arrangements.

Now it is time to get your creative juices flowing. In what kind of integrated, independent housing environment will your son or daughter thrive? What resources do you have or need? What steps can you take? Use the following charts to sketch out how several different integrated, independent housing arrangements could work for your family member. Each arrangement can be customized based on the individual's unique housing and service needs, eligibility for services and housing assistance, and access to housing and support providers.



Answering these questions will help you narrow the field of options. There may be several housing arrangements that would make your family member happy, healthy and safe, but if you cannot obtain certain housing, service or financial resources that are critical to the success of a particular arrangement, then it does not make sense to pursue this housing arrangement. Likewise, the steps you take to put a housing arrangement in place must be realistic and achievable. Finally, if you are likely to encounter insurmountable challenges or there is no clear, practical path to sustainability, then you may want to look at other options.

Regardless, putting your ideas down on paper is a great way to begin organizing your thoughts and developing a plan of action. Then, go back and look at the Helpful Links for more information on various resources, tools and experts. Finally, consult your DBHDS Regional Housing Specialist for assistance with learning about creative housing arrangements and navigating housing resources statewide.

Name of Housing Arrangement:

Will This Housing Arrangement Make My Son/Daughter Happy, Healthy and Safe?

What Aspects of This Arrangement Work for Your Family Member?

What Aspects of This Arrangement Would You Change?

What Required Resources, Tools & Experts Do I/My Child Already Have for This Housing Arrangement?

Service-Related Resources

Housing-Related Resources

Experts

Other Resources

What Required Resources, Tools & Experts Do I/My Child Need to Get for This Housing Arrangement?

Service-Related Resources

Housing-Related Resources

Experts

Other Resources

What Are the Steps We Must Take to Put This Housing Arrangement in Place? 1.

2.

3.
4.
5.
6.
7.
8.
9. 10.
What Challenges/Issues Are We Likely to Encounter?
<u>Challenges/Issues:</u>
How Will We Address These Challenges/Issues?
What Steps Must We Take to Make This Housing Arrangement Sustainable?
1.
2.
3.
4.
5.
6.
7.
8.
9.
10.