



# How-to for Setting Up a Supported Residence

## A Pathways to Adulthood Project

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Every family of a person with a disability has a unique pace for when their child will move out of their home. Some families answer the question, “When is your child moving?” with “Never!” and others say, “ASAP!” Factors in the pace will be your child's age, support and resource issues, your ability to care for your child, and your child's desire to live elsewhere. And each family has a unique vision for their child's future living arrangements. This guide is designed to start your thinking about a future home for your child. It provides ideas for decision making and for how to set up a residence that offers independence for your child coupled with safety and supports in place as needed—but only briefly. This guide will get the wheels turning but does not attempt to provide in-depth information. Note that there are several parent stories and a list of resources and articles on establishing a home at the end of this guide.

Imagine a home where your child could live separately from you and you would feel peace of mind most of the time about his or her living there. What if you could start now to plan for that place, in an orderly, thoughtful way so that when it's time, you're ready! It might be a year or 2-3 years from now, or maybe 10, but beginning to strategize now will pay off when the push comes for your child to move out.

Here are some of the assumptions that we who are writing this guide have made:

- You want a place for your child where most of us would like to live.
- The place is as integrated into the community as possible.
- The place has a maximum of 3 people with disabilities living together.
- The home reflects the preferences of the residents as much as possible.
- The home places control over the environment in the hands of the family or families and the residents as much as possible.

### The preliminary work

#### **Do some brain-storming about your child's future residence.**

List qualities—tangible and intangible—about the residence. Consider things that are important to you, such as what is essential for your child's safety and well-being. Now consider the qualities that you know are important to your child: these might include what your child prefers for fun, fellowship, privacy, independence, choice, etc. Draw a picture or photograph a place where your child would enjoy living. Consider doing this exercise with your child, with siblings and other family members, with others who know your child well. You might go through this exercise many times before you actually set up a residence.

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### **Participate in a person-centered planning (PCP) process.**

Facilitated and directed planning is a great way to start the discussion about what your son or daughter really likes and dislikes, what supports are needed, and what goals emerge as high priority. ([Info on PCP](#))

### **Consider setting up a personal network for your child.**

This network could help you make decisions, find and evaluate resources, and provide connections to the community. Through a network you can draft people who have energy, knowledge, resources and community ties that will assist you and your family in the process of developing a home for your child. If you are interested, see the TXP2P How-To for creating a personal network for your child.

([More info](#))

### **Go slowly.**

From the parents who have gone through this process, the consensus is that it will take a year or more to create a residence for your child. Build relationships with possible collaborators and house mates over time, discuss options thoroughly, and give yourself, your child and your family time to get used to the idea of this move.

## **The major decisions**

### **Decide on the living arrangements regarding house mates and supports.**

Here are some possible living arrangements: your child might

- live alone
- live with a care provider or family ( your child is the only person with a disability)
- live with house mates plus live-in assistance (a care provider or house parent)
- live with house mates with no live-in assistance; support staff can come and go as needed or perhaps natural supports are enough (people who aren't paid to assist your child, like house mates without disabilities, friends, neighbors, family)

### **Comparison of setting up a place for your child alone vs. working with other**

**parents:** Working alone is simpler for setting up and running a home but more costly. A shared residence is cheaper as you share costs with other families but is more complicated because you must make most decisions with other families; your own ideas and preferences will have to be altered to some extent and you'll have less control.

### **Considerations for a shared residence:**

If your child will be living with house mates, you will need to work very closely with the other parents of the shared-residence house mates.

If you are interested in a shared residence, you will need to find house mates for your child and will be working with their families. You might find other interested families through:

- disability support groups
- school peers

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- recreation/hobby groups like Special Olympics
- your own network—tell your friends, colleagues and family about your plans and see if they know someone who might be a house mate/collaborating family
- Texas Parent to Parent listserves, conferences and workshops

Remember, roommates might be peers without disabilities, such as a college student who needs low or reduced rent in exchange for some household responsibilities. Consider someone with different or less severe disabilities than your child--perhaps several house mates will bring different skills to fill in the gaps for the others.

Do your best to explore thoroughly the compatibility of both children and adults. Key questions will be: Do the roommates get along and have compatible life styles? What are the management styles of the different parents and how involved do they wish to be? Consider the level of control each family will have over hiring and managing staff. Consider all legal and financial agreements; you must end up with all such agreements written down.

One option for setting up a shared residence is through a Family Consortium, whereby families work together to create a home. Whether to set up a consortium or just to learn more about how to set up a shared residence, look at the outstanding and very thorough resource at [Leapinfo.org](http://www.leapinfo.org), a non-profit in Ohio. This resource helps families make decisions about setting up a shared residence and a Family Consortium: it provides extensive information on every topic, such as how to work with other families, the steps to buying and renting and the advantages and disadvantages of each choice, using technology to cut down on human support costs and promote independence, how to write a budget, sample legal agreements and much more.  
(<http://www.leapinfo.org/home-community/living-with-technology/the-illp>)

### **Secure funding for rent, mortgage, or remodeling your own home and household expenses.**

Another major step is to consider the financial requirements for setting up a separate residence for your child. Renting a home, condo or apartment gives you more flexibility while you try out a new situation, while buying a home or condo provides permanency. Another option preferred by some families is to adapt, add onto or remodel part of the family home to create an independent living space for your child. Most of these choices will involve doing research on the options in your community and conferring with lawyers, realtors, and financial institutions. Be sure to investigate local assistance for low income, people with disabilities and first-time home owners.

- Will you rent a house, condo, duplex or apartment, and who will sign the contract?
- Will you buy a house, condo or duplex and who will be the purchaser?
- Will you modify your own home or use or build a separate place on your property? (for example, MedCottage, for someone with high level of medical and mobility needs; see Resource List at the end of this document)
- Will more than one family purchase or rent the property? Consider a Family

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## Consortium

If you buy a home, who will own the home?

- Occupant owned
- Parent or relative owned
- Joint ownership (several families)
- Trust ownership
- Corporate ownership
- Nonprofit agency

Think about your price-range for monthly mortgage payments, and remember to include down payments or deposits, property tax, home or renters insurance, legal fees, and furnishings.

Write a budget for household expenses, based on your own household expenses and knowledge of local amenities. Remember to include utilities, cable/phone/internet connections, food and household supplies, and transportation. What are the tax considerations for your child and family?

List financial assets and resources available to you and your child to meet these expenses. Some possibilities are:

### Public funding:

- Social Security assistance (SSI or SSDI) can be used to pay for household expenses.
- Some Medicaid Waiver programs can be used to provide a home
- Food stamps (called SNAP)
- Low income, subsidized housing

### Private funding

- special needs trusts, family funds
- your child's work income
- rent and expenses paid by roommates

### Using a Medicaid Wavier Program

Note that each public and state funding source has its own rules about what it can be used to pay for and with whom the funded recipient can live. For any Waiver, using the Consumer Directed Services or CDS model will provide much more choice over staffing issues. If your child has a Medicaid Waiver program, become familiar with what options exist regarding a residence. This chart at the DADS website states what each program provides and allows: [http://www.dads.state.tx.us/providers/waiver\\_comparisons/](http://www.dads.state.tx.us/providers/waiver_comparisons/)

### **Secure supports that your child will need to live a safe and positive life**

Most people with disabilities will need some level of support for daily living. Some will need help with each daily living activity, while others may only need a daily or weekly check-in to be sure the person is, for example, eating well, paying bills, in good health, and getting to work.

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To determine the level of support your child will need and key times of the day/week when supports are most needed, designate a period of time to record your observations about your child's support needs. One way to do this is to keep a record for a week or more of how you now assist your child. You might keep a log of all your contacts with your child for a few days, including sick days, weekends and holidays. Another way is to consider your child's current level of functioning in a variety of areas, such as eating, bathing, dressing, taking medications, getting places, and so on.

- How much supervision is needed for your child's safety?
- When are key times for support?
- What kind of routine and daily rhythm does your child need?
- What exceptional medical or behavioral supports are needed?
- What skills might your child acquire that would lead to more independence?
- How could you use technology to promote independence and lower human support costs?
- What precipitates a crisis and what needs to be done at that time?

Here are some ways that support might be provided:

- paid staff
- live-in support person
- technology (use the internet to keep up with this constantly expanding area; note assistance technology for seniors) (The LEAP project has extensive information on technological solutions)
- roommates with lower support needs
- natural supports such as friends, neighbors, family members
- someone who is not paid but gets free home and board

Some people who might provide some supports in exchange for free room and board include students; people whose living circumstances have recently changed; retirees; people who are highly motivated by a cause, spirituality, or interest in or passion for learning about disabilities.

Here are possible funding sources for support and care providers:

#### Public funding:

- Social Security assistance (SSI or SSDI) can be used to pay for care providers
- Medicaid Waiver programs all pay for some kind of attendant care, support staff, etc For any Waiver, using the Consumer Directed Services or CDS model will provide much more choice over staffing issues. This chart at the DADS website states what each program provides and allows:  
[http://www.dads.state.tx.us/providers/waiver\\_comparisons/](http://www.dads.state.tx.us/providers/waiver_comparisons/)
- Local Authority for Intellectual and Developmental Disabilities

#### Private funding

- special needs trusts, family funds
- your child's work income
- rent and expenses paid by roommates
- family and friends who can provide time and effort to support the residence

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### **Find a place and set a time-table for moving in!**

Finally, you will arrive at the step of finding a place. Some of the considerations for where you will look are:

- safety of the neighborhood
- proximity to public transportation, stores, work opportunities, recreation, medical facilities
- proximity to family and friends
- proximity to public transportation
- neighborhood restrictions

Some considerations for the kind of place you look for are:

- big enough for sharing with roommates and space for live-in staff
- not too big for care, maintenance, and affordability
- accessible for wheelchair or other physical issues
- compatible with the preferences of the residents
- resale value

### **Organizations that might help with renting and home ownership.**

**Texas Home Programs** provides a summary of housing-related programs for homebuyers in the state of Texas. A number of programs provide homebuying assistance to individuals based on income. The Texas Home Programs Web site and educational programs are made possible by the Texas Association of REALTORS® with the assistance of other community-based organizations. Go to <http://www.txhomeprograms.org/index.php>

**HOYO or Home of Your Own** provides information, classes, a downpayment and closing costs to people with disabilities or their families to purchase a home.

<http://centraltx.easterseals.com> and [serach with HOYO](http://serachwithHOYO.com)

*Look for a local business that helps people find rental properties. Search for a rental agent who is sensitive to the individual needs of the renter or has some experience in this field.*

### **Prepare for a healthy transition.**

Be aware that your child's move is a life-altering transition. You may feel heightened anxiety, a sense of loss, a feeling of losing control, and at the same time a sense of new freedom for yourself and new energy for your own life. Your child may surprise you by being eager to move; this anticipation is not a rejection of you but part of the normal transition most adults go through. Your child may also show emotional regression or cling to you, or be adamant about remaining at home. These are all normal reactions to change. You, your family and your child will most likely adapt over time to the new arrangements and come to appreciate them. Know that your support and participation will be crucial to the success of the move and the on-going life at the new residence. Keep in mind that you are working to increase your child's independence and to secure

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his future for a time when you may no longer be available to provide as much care and intervention as you do now.

### **Look ahead.**

You will also need to look ahead to the running of the residence. You may need to develop a system of monitoring and a list of responsibilities. Consider:

- Who will provide quality control?
- Who will check in to make sure that things are going well?
- Who will deal with staff changes and issues?
- Who will train new staff?
- Who will be responsible for paying bills, setting up doctor appointments, etc?
- Do you need a system for staff to make notes or keep a journal for daily observations?
- Do you need to have regular meetings of staff, other parents and house mates?

### **Some additional ideas for living arrangements:**

#### **If your child has the HCS Waiver (Home and Community-based Services)**

- Parent take-over of an exiting HCS Medicaid Waiver group home—in this model from Ohio, parents shopped around for a group home owner who was open to parent input; parents formed a Family Consortium to run the group home. The advantage—parents don't have to buy and staff a home, the Waiver does that, but parents can maximize their control over decisions about the home.
- A parent can start an HCS group home.
- See more at <http://www.dads.state.tx.us/services/intellectual/getservices.html>
- Explore the idea of using a Microboard to run a group home. See the Arc of Texas website for the Microboard Collaboration. ([Thearcoftexas.org](http://Thearcoftexas.org))

#### **Other ideas**

- Talk to people in your area who have started a group home or other kind of living arrangement about how to get started.
- Join a local parent group or start one (we can help at [txp2p.org](http://txp2p.org)) so that you'll get to know other parents who might be interested in forming a Family Consortium or some other shared residence project.
- Arrange for your child to live with someone for a transition year, with the plan of moving into a more independent setting. For example, a special ed teacher might open her home to a student during the last year or 2 of school, knowing that the person will be there only for a limited time. This plan allows the student and family to explore and learn about what will work and what direction to head.
- Request the services of a Behavior Analyst, Case Manager, or Life Coach to help you figure out what living arrangements will work and to develop a housing plan.
- Parents who are exploring a Family Consortium might consider going to group therapy together for a few sessions. It will be of utmost importance to know how the different group members react in a crisis, how much control each person will need to feel comfortable, who is good at what, what roles each person is likely to fill.

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- Call the DADS Regulatory Specialist or your Local Authority to explore seldom used funds or programs for moving your child into his or her own place. You can find the Regulatory Specialist in your area at <http://www.dads.state.tx.us/employment/regsvcs/> and your Local Authority for Intellectual and Developmental Disabilities at <http://www.dads.state.tx.us/services/contact.cfm>

### **Conclusion**

Below are the stories of several families who have gone through this experience. And following is a list of websites and resources useful to the process of moving your child into his or her own residence. We wish you luck in this endeavor and encourage you to find supports and collaborations in your community and through Texas Parent to Parent. Please stay in touch with TXP2P as we continue to assist parents in building a high-quality home for their children as adults.

### **Texas parents tell you about their experience with setting up a residence:**

#### **My experience in setting up a home for my son**

James had previously lived in a large group setting, and also in a group home. Neither had been enormously successful for him. After his name came up on a waiver list, I was motivated to move quickly to get him into his own home. I knew I didn't want to leave James in a group home as I wanted control over who he lived with, where he lived, and the staff who worked with him. I decided to rent a home for him, and we had a house mate willing to move in.

Fortunately the parents had planned ahead and we wrote out all our agreements on paper, including an agreement as to how to separate. We purchased all household furniture and goods, splitting everything except personal items. We each used waivers to pay for staff to be present with our sons during the hours they needed assistance. Unfortunately, after a few months, it was clear our parenting styles were vastly different, and we decided to end the living arrangement. I then bought a house for my son to live in, close to where I live, and he has lived there for many months by himself and with staff. James' SSDI pays his portion of rent, food and living expenses, and he now has a new house mate with disability who also pays his own share of these expenses. Staff is present in mornings and evenings, and James has scheduled activities, including work, during the days. I choose to hire and pay staff through the consumer directed services option (CDS) which allows me to determine their rate of pay, as well as hire them directly. I can also pay them at a higher rate since their employment doesn't go through a "provider". Because James is on HCS, paid staff cannot "live in" the house; I have one staff who works the first part of the week and another who works the second part of the week. Weekday staff members typically don't work for James from 10 am until 5 pm, which allows them to go to school or work at another job. Other staff works weekends. James helped me select all staff, and loves being with them. This living situation is ideal for James and has been wonderful for our family. The staff is

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well trained and I am comfortable that he is safe, happy, and learning independence. We have staff meetings once a month where staff can get together and share ideas that enhance James' quality of life in all ways. It has been difficult to get all the system working well, and it has been expensive. It has also consumed a great deal of time and energy from me and continues to do so. All of this is worth it because of the good situation my son is in. I expect it will continue for a long time.

### **Shared Parenting, a personal perspective**

When my son Will was 20, my husband and I felt worn out. We had been caring for a person with severe disabilities for 20 years and were feeling old and cranky. Our second son was about to leave for college, my mother was ill and needed me, and it felt like a turning point. So we created an arrangement that I now know to call "shared parenting." My son moved in with another family, to live there and visit us frequently.

About family # 2:

- mom # 2 had been my son's special ed teacher for 2 years in high school
- she had already had Will in her home often as a respite provider
- she is a generous, warm-hearted person
- she was looking for a second income
- she has 2 sons of her own

About us:

- we still wanted to be very involved
- we are Will's guardians
- we needed a change
- Will is on the CLASS Medicaid Waiver program and receives SSDI

Our arrangement:

- Will lives at the other house; at times he has had his own room, and at times has shared a room as their family circumstances have changed
- he brings income to their family of 40 hours/week of CLASS attendant hours and his SSDI
- other CLASS attendants take him out each week day for activities
- I am in charge of shopping for clothes, shoes, etc, taking Will to doctor appointments, and managing the CLASS hours and activities
- Will comes home once a week without fail for 4-6 hours and we see him other times for fun or as needed
- mom # 2 and I sit down together once a week, usually for an hour, to talk and plan
- Will stays with another attendant 2 weekends each month
- Will, at age 31, has lived with this family for 11 years now

I buried my mother, joined the gym and re-discovered my relationship with Will. Now, instead of talking about Will as having severe disabilities, I talk about him as a person with a great laugh and smile and a joy to be with; I look forward to our time together!

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