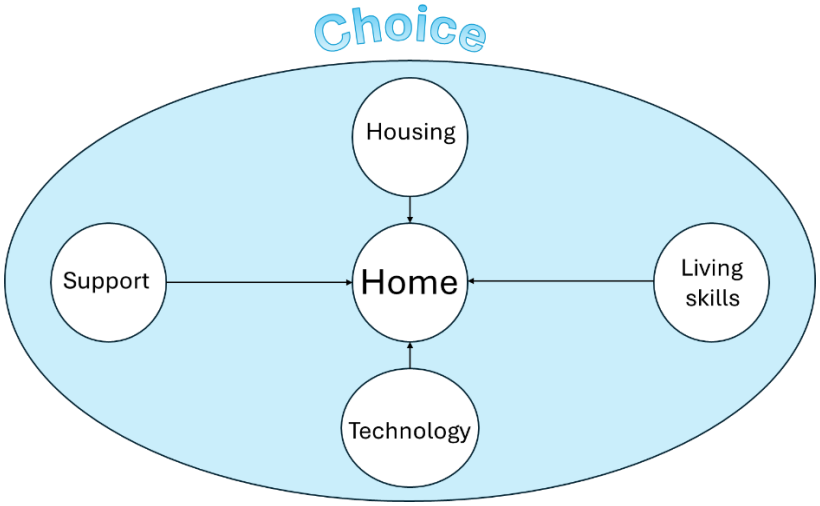
Home

Catherine Boyle, Autism Housing Pathways, April 2025

The title of today's session is "Developing a housing strategy." I want to strike a line through that and say that today's session is about the concept of "Home." A definition of home from Duck.ai states that: "A home is a place where a person lives, often with family, and can refer to a house, apartment, or any dwelling that provides shelter and a sense of belonging. It can also represent a familiar environment or a place where one feels secure and comfortable." I would simply put it as home is a place where you live and feel comfortable in your own skin. Our goal is a home, not a placement.

If we come at this from a person-centered planning approach, we can identify a housing North Star. Our North Star is our ideal. Here is a schematic of a housing North Star:



Housing North Star

Housing exists as an element within our North Star, as one of the pillars supporting a home, but it is not a home in and of itself. We can describe it, flippantly but also accurately, as “three hots and a cot.” Living skills are the skills we bring to bear to support living in the home. But not everyone is on a level playing field when it comes to living skills, so this is where technology can come in. It is also where support comes in, but I want to make it clear that support is a much bigger concept than supportive services. Support also encompasses the emotional support necessary to be comfortable in our own skin, to actually be at home in our home.

But the North Star is an ideal, something to strive toward. We should always have one, but that does not mean we will always achieve it. My personal experience is that there are no rainbows and unicorns in adult services. Systems are structured around funding, staffing, eligibility, and contractual payment codes, whether we are talking about a full-blown group home or drop-in services in a subsidized apartment. Because of these limitations, I sometimes see people turning down housing options because they do not match up to their vision. We can liken this to turning down a perfectly serviceable carthorse because it is not a unicorn. The problem is, if we wait too long, when a crisis occurs, we may not even have access to the cart horse.

Instead, it can make sense to give the cart-horse unicorn lessons.

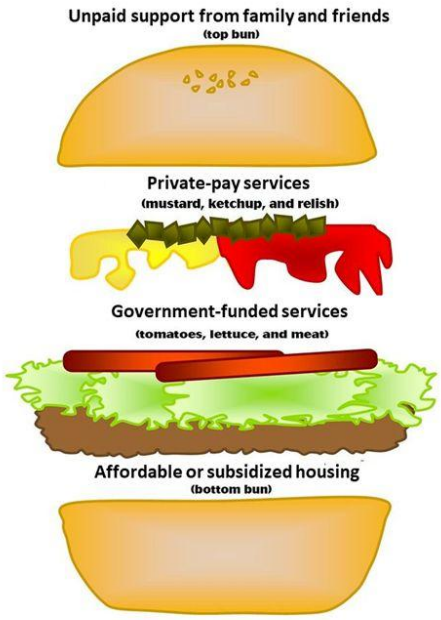
Giving a cart-horse unicorn lessons.

What do I mean by that? I mean that, because systems are the primary payment sources for housing and services, we need to use them – but we should not be restricted to them. We can also tweak systems over time to improve the fit. In general, it is easier to adjust systems once we are in them than it is to access them from outside. In other words, do not let the perfect be the enemy of the good. To give a concrete example:

- A parent has been offered a group home placement for their daughter, but they would prefer the housemates were younger. The reality is that there is a dramatic shortage of group home beds. The home they have been offered is at least all women, which is important to them, and close to home. It makes sense to take the bed for now and keep an eye out for other options. Additionally, it is possible their daughter may wind up liking the housemates.

In general, we cannot assume that any housing situation will be optimal off the shelf. Tweaking needs to occur. So what does this look

like? We can think of supported housing as a sandwich, more specifically a hamburger.



Supported housing is a sandwich

Cap your sandwich off with unpaid support from family and friends

Private-pay services are the condiments (go light on this if you can)
- If your family member needs additional support, you may need to pay for some of it

Government-funded services is the meat
- These can include services from DDS and MassHealth, or federal benefits, such as Social Security and SNAP

Affordable or subsidized housing is your bottom bun
- The subsidy may be attached to a specific unit or it might be a portable voucher

In our hamburger, the bottom bun is some form of housing subsidy, whether attached to a unit or in the form of a portable voucher. Anything else you can get the government to pay for is the burger. Private-pay services and supports are the condiments, like mustard and ketchup. The top bun is unpaid support from family and friends. Everyone has a burger, but everyone's burger looks different. We also need to maximize the bottom bun and burger, so that our money will stretch far enough, and we do not completely burn out family and friends.

So how do we get there? Let's build our burger one layer at a time. We will start with applying for affordable and/or subsidized housing.

Section 8 Housing Choice Voucher Program (portable)

- Individual pays 30% of income in rent to landlord; the balance is paid to the landlord with funds from the US Dept. of Housing and Urban Development
- Will not affect SSI or Medicaid benefits
- Can be a 10-12 year wait in Massachusetts
- A family member can be the landlord as a reasonable accommodation, but the person renting must live in a legal, separate unit
- If the person needs a live-in aide, they can receive a two-bedroom voucher, and the aide's income is not considered (provided the aide is not a "natural" part of the household)
- http://affordablehousingonline.com/open-section-8-waiting-lists

Finding "other affordable housing"

- HUD subsidized apartments: http://www.hud.gov/apps/section8/index.cfm
- USDA Rural Development Multi-Family Housing Rentals: http://rdmfhrentals.sc.egov.usda.gov/RDMFHRentals/select_state.jsp?home=NO
- Public Housing Authorities: http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/pha/contacts
- HUD-approved Housing Counseling Agencies: http://www.hud.gov/offices/hsg/sfh/hcc/hcs.cfm
- State Housing Finance Agencies: https://www.ncsha.org/housing-help
- In Massachusetts: www.18section8.org

Public Housing Authorities may have multiple types of units, ranging from dedicated apartment complexes to scattered-site units in larger market-rate buildings, or even houses. In Massachusetts, these are the agencies that run elderly housing with set-asides for younger people with disabilities.

HUD-approved Housing Counseling Agencies should be familiar with other affordable options in your community, such as housing made affordable by tax credits. Another source for that information may be your state's housing finance agency. For instance, on MassHousing's website you can search for affordable apartments. Please note that this slide is for a national audience. A much more granular approach for Massachusetts can be found at our website, www.18section8.org.

Now that we have talked about our bottom bun, let's move onto our hamburger, anything else that the government will pay for.

Funding streams

Bricks and mortar expenses	Food	Supportive services
SSI	SSI	SSI
SSDI	SSDI	SSDI
Section 8	Food stamps (SNAP or Bay State CAP)	MassHealth (Medicaid)
Other "affordable housing"	DDS	DDS
DDS	DMH*	DMH*
DMH*	Private resources	Private resources
Energy/utility assistance		
Private resources		

SSI, SSDI, DDS, and DMH can be used for housing, food, and supportive services. Other funding sources can ONLY be used for the column they appear under.

*Rarely accessed in practice by people with autism

Our chart of funding streams begins with what I call the housing equation, which is: Bricks and mortar expenses plus food plus supportive services equals bare bones housing. Under each of these is a column of resources that can be used to pay for them. Under bricks and mortar are SSI, SSDI, Section 8, other affordable housing, a Developmental Disability (DD) agency (in Massachusetts, the Department of Developmental Services), DMH (the Department of Mental Health), energy and utility assistance, and private resources. Under food are SSI, SSDI, food stamps (SNAP), the DD agency, DMH, and private resources. Under supportive services are SSI, SSDI, Medicaid (MassHealth in Massachusetts), the DD agency, DMH, and private resources. SSI, SSDI, the DD agency and DMH appear in all columns, while other resources only appear in one column. While we have already covered affordable housing, it appears on this chart so you can see how it fits into the full range of funding streams that can be accessed to support housing.

Cash benefits from Social Security

- SSI
  - Cash benefit of $967/month in 2025 (adjusted based on the living situation)
    - Some states supplement this
    - Benefit may be reduced, based on income from other sources
  - Makes you eligible for Medic**aid** (pays for long-term services and supports)
  - Can be used for housing or services; has income and asset limits
- SSDI
  - Based on the work history of the parent or of the individual
    - If based on parent's history, kicks in when parent retires, becomes disabled, or dies
  - Usually pays more than SSI
  - Makes you eligible for Medic**are** (does NOT pay for long-term services and supports)
  - Can be used for housing or services; has fewer income, asset limits

A key element in our funding streams is a cash benefit from Social Security in the form of SSI, SSDI, or a combination of the two. Eligibility for SSI, or Supplemental Security Income, is limited to individuals who are elderly, blind or disabled, have extremely low income, and countable resources of less than $2,000. The federal SSI benefit is $967/month in 2025, which is supplemented by some states, with the amount of the supplement based on the living situation. The federal portion of the benefit is reduced, if the individual is receiving either cash or in-kind support from someone else. Individuals can receive $65 in earned income and $20 in unearned income in a month. Anything further will result in a reduction in the amount of SSI an individual receives (of up to 1/3 of the federal portion of the benefit, plus $20). In most states, being on SSI as an adult makes one eligible for Medicaid, which pays for long-term services and supports.

Some individuals receive SSDI, rather than SSI. SSDI is Soc. Security disability. Eligibility can be based on the work history of the individual or of a parent. The amount paid depends upon work history. An individual qualifying based on a parent's work history is eligible to receive SSDI when a parent dies, retires, or becomes disabled. In many cases, SSDI pays more than SSI. There is no savings or asset limit to qualify for SSDI, and unearned income will not affect the amount of the benefit. There is a limit on earned income: $1,620/month in 2025. The bad news is that SSDI doesn't automatically make you eligible for Medicaid. SSDI makes you eligible for Medicare after 2 years, but you cannot use Medicare to pay for

long-term services and supports. Please note that if an individual moves from SSI to SSDI ***as an adult***, they cannot lose their Medicaid if that is the only reason their income now exceeds the cap for Medicaid eligibility. The implication is that parents may need to delay retirement until after their child is on SSI as an adult.

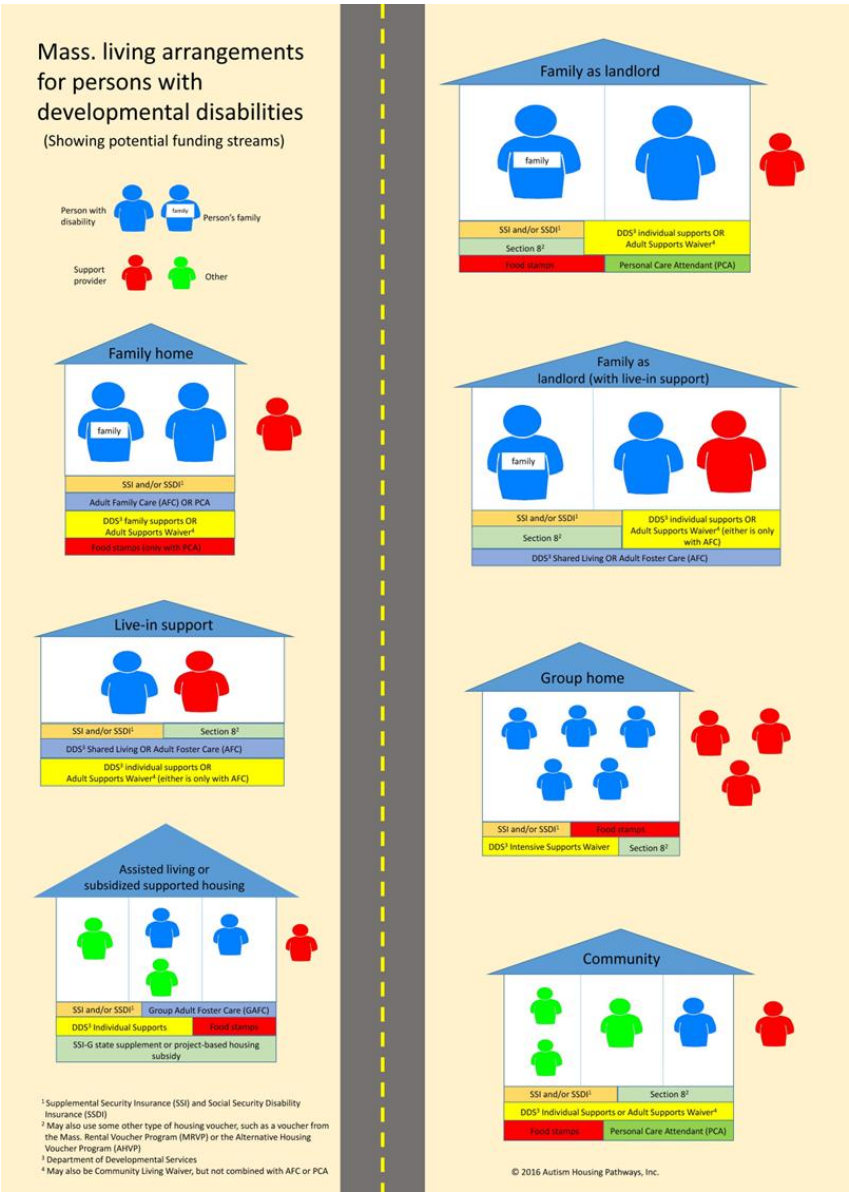
Medicaid

- The main way to pay for services
- Operates like a cafeteria plan: different states offer different options
- Home and Community Based (HCBS) waiver services (offered under 1915(c) of the Social Security Act) can have waiting lists and caps on the number of people who receive them
- HCBS State Plan Services (offered under 1915(i) of the Social Security Act) do NOT have waiting lists or caps

I want to say a few things about Medicaid. Medicaid is the main source of funds to pay for long-term services and supports. While there is a lot of talk about Medicaid Home and Community Based Services waivers, which are under 1915(c) of the Social Security Act, waivers have caps on the number of people who can receive them and frequently have waiting lists. Medicaid state plan HCBS services, under 1915(i) of the Social Security Act, by contrast, are an entitlement, meaning if you qualify for it, you have to receive it, and there can't be a waiting list. Please note that if Medicaid adopts either block granting or capitation, there may well be waiting lists for state plan services.

Medicaid state plan HCBS services vary wildly from state to state, and a service that may be available as a state plan service in one state may only be available as a waiver service in another. Examples of state plan HCBS services in Massachusetts are Adult Family Care or Adult Foster Care, which pays a stipend to a live-in caregiver, and Personal Care Attendant services. Medicaid prohibits “duplication of care”, so generally state plan services that serve a similar purpose, such as residential supports, can’t be combined. Thus, in Massachusetts, you can’t combine Adult Family Care with Personal Care Attendant services, for example.

Using the funding streams identified, including housing subsidies, it is possible to build a typography of possible housing models, using Massachusetts as an example. Before doing so, however, we need to be aware that, due to MassHealth and DDS policies and regulations, not all funding streams can be used in all situations. Taking these limitations into consideration, there are seven basic housing models in Massachusetts.



The infographic shows each model, with a breakdown of the funding streams that can be used in each one. They are:

- The family home: a non-custodial family member provides support, or support comes in periodically.
- The family as landlord: the individual lives in an attached unit, with support than comes in periodically.
- The family as landlord (with live-in support): the individual lives in an attached unit, with live-in support

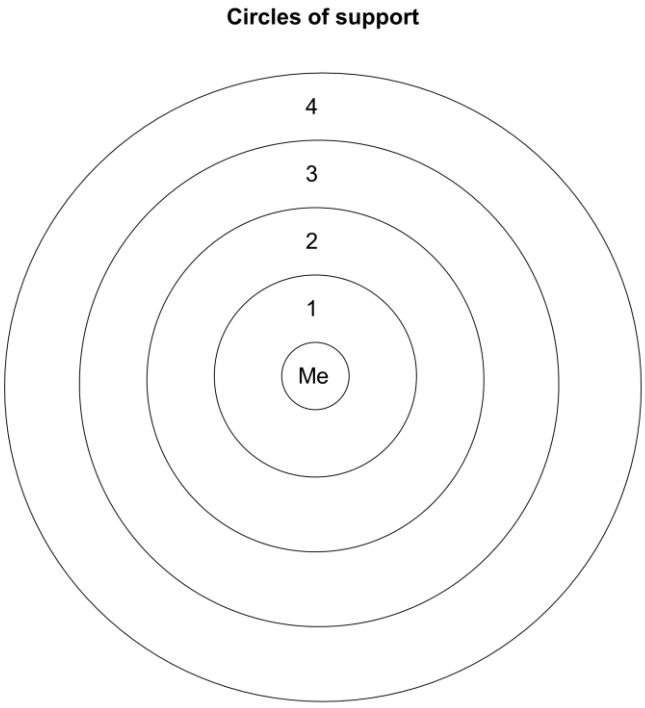
- Live-in support: the individual lives in a separate unit, with live-in support. The unit may be owned or rented by the individual, the family, or the support provider.
- A group home: a number of people live in a small group residence, with support provided by hourly workers provided by the state or an agency. The home may be owned by families, the state, an agency, or a third-party landlord.
- Assisted living or subsidized supported housing: individuals may live in an assisted living facility or subsidized housing, with support that comes in periodically.
- Community: an individual lives in an apartment or home in the community, with support that comes in periodically.

There is actually a broad range of creative housing models possible that can be fit into this typology.

But the truth is that this typology has holes in it. The identified funding streams will not completely cover the costs in most cases, which brings us back to our supported housing sandwich, specifically to the condiments, which are additional paid supports and services, and the top bun, which is unpaid support from family and friends. This is where the carthorse really starts working on its unicorn lessons.

In terms of paid supports and services, there are agencies that provide private coaches and drop-in services, as well as some that provide private pay group living situations for those who need relatively little support. Assistive technology may be an additional cost. While in some situations, DD agency or Medicaid dollars can cover part of these costs, in others they cannot.

Beyond paid support (and when paid support is not affordable), we are left with the unpaid support of family and friends. This, too, is not an inexhaustible resource, but it is one that can be cultivated to good effect. To understand this let's look at a model of Circles of Support.



1. Circle of intimacy
2. Circle of friendship
3. Circle of participation
4. Circle of exchange

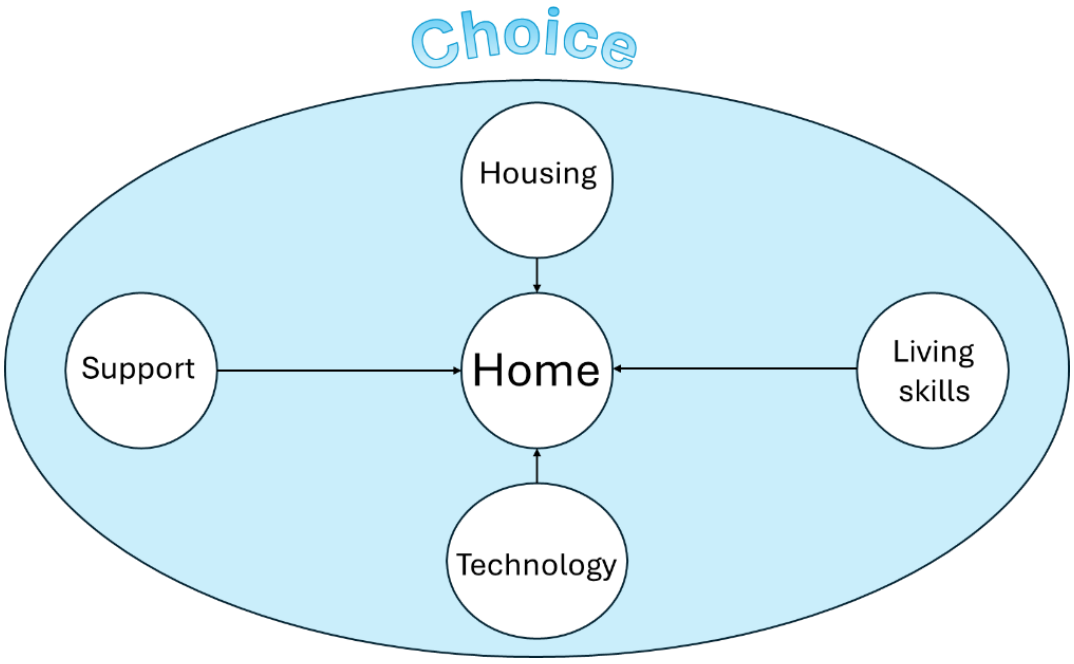
(Adopted from O'Brien, et al., The PATH & MAPS Handbook: Person-Centered Ways to Build Community, Inclusion Press, 2012.)

A good, free handbook on cultivating Circles of Support is at https://tinyurl.com/y3pz9626.

In the drawing, we have a set of five concentric circles. The innermost one is labeled "Me." The remaining four circles are labeled 1 through 4, with 4 being the outermost. Circle 1 is our closest family and friends. Circle 2 is comprised of less close family and friends. Circle 3 is comprised of the people we meet going about our daily life. Circle 4 is comprised of the people paid to be in our life. In other words, all the services and supports we have talked about up until now only fit in Circle 4.

The truth is that everyone has circles of support, it is not a disability specific concept. But people without disabilities tend to have a roughly even number of people in each circle, while those with disabilities have people concentrated in Circles 1 and 4, with the number in Circle 1 dropping as they age. Our challenge is to cultivate and engage people for Circles 2 and 3, without putting too much pressure on any single person. This work is ongoing, needs to start early, must be something consciously undertaken, and is not something we can generally expect the human services system to do for us. It is particularly important to recognize that Circle 4, also known as the circle of exchange, is different from Circle 2, also known as the circle of friendship. When we rely on paid caregivers to be friends, we set ourselves up to be devastated when they need to leave.

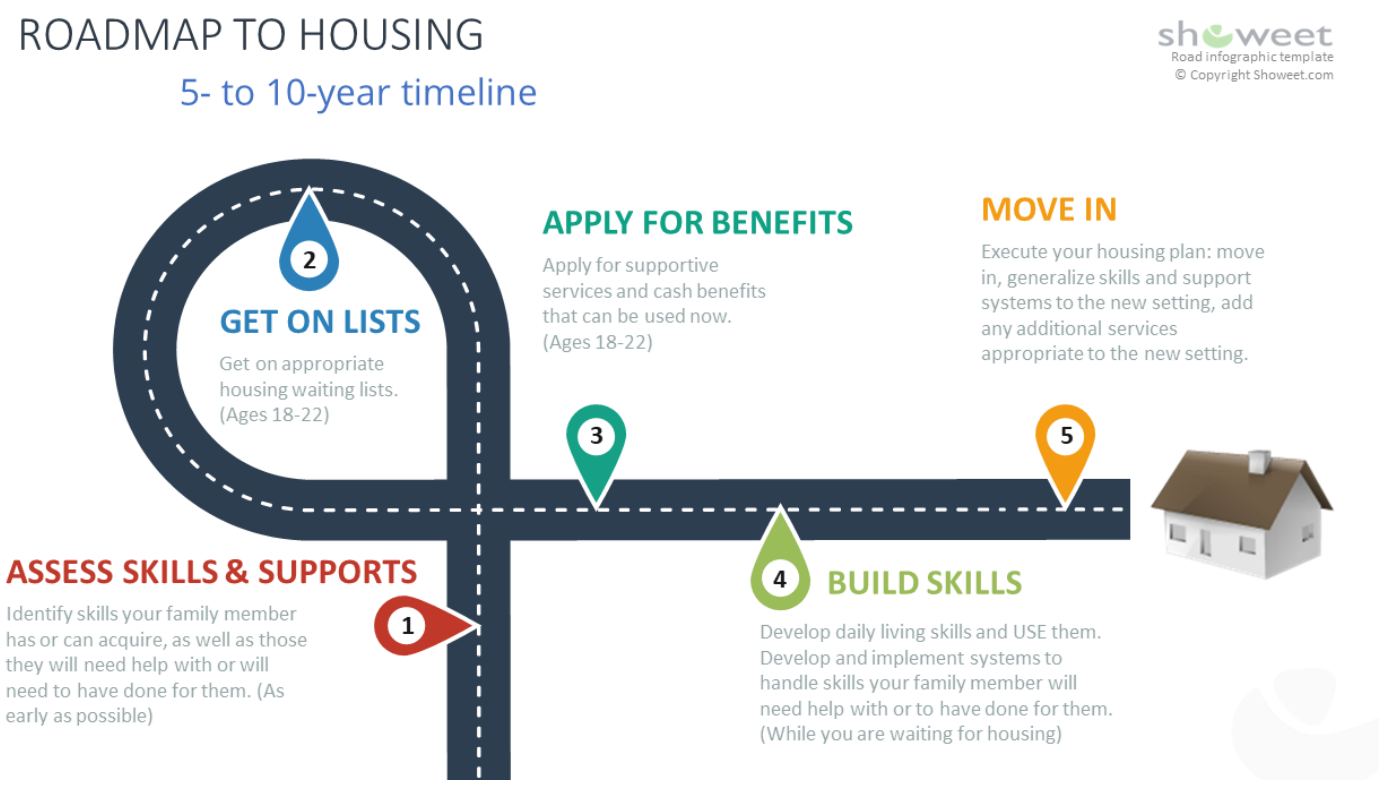
If we revisit our initial North Star, you can see we have touched on all the elements accept one, which is Living skills.



Housing North Star

Technology can be used to support gaps in living skills. Supportive services can do the same. But the truth is that, while not everyone can master all needed living skills, we need to maximize obtainable skill development, so we don't burn out our circles of support, both paid and unpaid. A good place to start is with skill assessment. We can divide skills into four categories: 1) those a person has and actively uses; 2) those they can learn to actively use; 3) those they will always need some help with; and 4) those that will need to be done for them. Overall, we need to move as many skills from category 2 to category 1 as possible, while identifying systems and supports (both paid and unpaid) for categories 3 and 4.

With all these concepts in mind, we can now introduce our final visual, the Roadmap to Housing. The roadmap presents a 5-to-10-year timeline, with five stops along the way. They are:



1) Assess skills and supports: identify skills the person has or can acquire, as well as those they will need help with or will need to have done for them. This can be done before the age of 18.

2) Get on lists: get on appropriate housing waiting lists. Ideally this should be done between the ages of 18 and 22.

3) Apply for benefits: apply for supportive services and cash benefits that can be used now. Ideally this should also be done between the ages of 18-22.

4) Build skills: develop daily living skills and USE them. Develop and implement systems to handle skills the person will need help with or to have done for them. These systems will draw upon your circles of support, both paid and unpaid. This step is our key activity while waiting for housing.

5) Move in: execute your housing plan: move in, generalize skills and support systems to the new setting, add any additional services appropriate to the new setting.

While the destination at the end of the road may be less than ideal, we can set a goal of ongoing improvement. We can strap a horn on our carthorse and keep riding toward our North Star.