

# Learning About Housing For Your Adult Family Member With Disabilities

Autism Housing Pathways



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## Isn't there a happy ending?

“Books ought to have good endings. How would this do: *and they all settled down and lived together happily ever after?*”

‘Ah!’ said Sam. ‘And where will they live? That’s what I often wonder.’”

- J.R.R. Tolkien

- 81% of young adults 19-30 with autism live with parents or guardians
- 67% of adults with disabilities aren't working
- 80 - 90% of adults with autism aren't working

(Easter Seals, 2008)

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## Won't my family member go into a group home?

- Adult services are not an entitlement
- 927 individuals who turned 22 in FY17 were served by the Department of Developmental Services (DDS); it is estimated about 40% - 50% had autism
- Only about 270 of the Turning 22 class received Community Based Residential Services (CBRS). CBRS includes:
  - Group homes
  - Shared Living, where a caregiver receives a stipend from DDS to live with a person with a disability (usually in the caregiver's home, but sometimes in the home of the person with a disability)
  - People living with a caregiver funded by MassHealth, who also receive 30 or more wrap-around hours a week from DDS

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## Who receives Community Based Residential Services?

- Historically, 25–30% of those receiving residential supports have no family involvement.
- For those with family involvement, DDS uses a “health and safety” criteria; if the person is living in the family home, and DDS feels they are healthy and safe there, DDS won’t fund CBRS, other than some “family support” hours.

## Who receives Community Based Residential Services (2)?

- Health and safety is a three-pronged test:
  - The family’s ability to provide care
    - Examples of someone receiving CBRS include a mother who is legally blind, a parent with a bad back who can’t provide care to someone in a wheelchair, etc.
  - The needs of the individual
    - Examples of someone receiving CBRS include individuals with aggression, self-injurious behavior, and pica (eating garbage)
  - The judgment of the DDS person doing the assessment
- If your child is offered housing at 22 and you turn it down, you may not be offered it again until the family is unable to provide care

## What about that group home?

- About 40% of those receiving CBRS live in a group home, and about 20% live in Shared Living
- DDS wants to serve more people in Shared Living, and fewer in group homes
- DDS does **NOT** fund the housing expenses in Shared Living
- People without an intellectual disability are not currently eligible for either a group home or Shared Living.
  - If they live in homes of their own and need less than 24/7 care, they may be able to receive individual support hours. Otherwise, they are eligible for family supports.
  - DDS will not fund the housing, except possibly if the person has no family involvement

**Most families will need to face the challenge of finding or creating housing**

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## The Good News: Separation of Housing From Services is Best Practice

- Finding housing is challenging, but can lead to better outcomes
  - Individuals can choose with whom they live
  - If the service provider is a poor fit, the individual can change providers without moving
  - If a live-in caregiver quits, the caregiver leaves, not the person with a disability

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## Don't Panic! Plan\*

### • Learn the Housing Equation

- Rules govern which government programs can be combined, which can't, what they can be used for and where

### • Develop a housing strategy that you can implement over time; 5-10 years is not uncommon

- At 18, start taking concrete steps
- Don't wait until you're ready for your family member to move out – because when you start taking steps is when the 5-10 year clock starts!

### • Develop assets (before 18, if possible!)

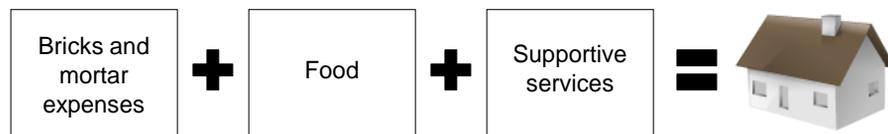
### • Develop your family member's skills

\* Nothing here constitutes legal, financial or real estate advice

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## The housing equation

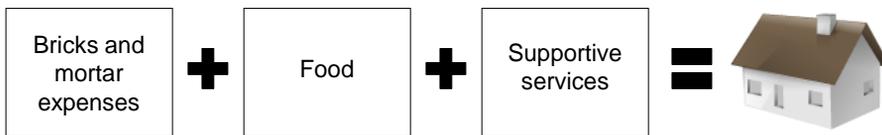


- Supportive services almost always cost more than bricks and mortar expenses
- Don't forget this doesn't include spending money, transportation, etc.

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## Funding streams



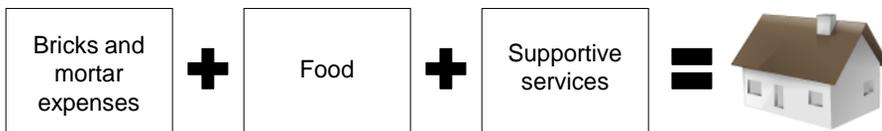
SSI	SSI	SSI
SSDI	SSDI	SSDI
Section 8	Food stamps (SNAP or Bay State CAP)	MassHealth (Medicaid)
Other "affordable housing"	DDS	DDS
DDS	DMH*	DMH*
DMH*	Private resources	Private resources
Energy/utility assistance		
Private resources		

\*Rarely accessed in practice by people with autism

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## Funding streams



SSI	SSI	SSI	<div style="border: 1px solid black; padding: 5px;">                 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.             </div>
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	Private resources		

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## The Big 4: SSI, SSDI, Section 8, MassHealth

### • Supplemental Security Income (SSI)

- Must be elderly, blind, or disabled, extremely low income (<\$1,337/month in 2017) and <\$2,000 in assets
- \$577-\$1,189/month, depending on living situation
  - \$1,189 in licensed assisted living
  - \$849 living alone
  - \$765 sharing expenses equally or in a group home
  - \$577 in the home of another where not sharing expenses equally
- Some is paid by the Social Security Administration, the rest by the state
- No penalty for \$65/month earned income, and \$20/month unearned
  - More income means benefit cuts of 50 cents on the dollar
  - The maximum reduction is 50% of the federal payment, plus \$20

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## The Big 4: SSI, SSDI, Section 8, MassHealth

### • SSI (continued)

- Makes you automatically eligible for MassHealth Standard
- Apply for SSI as an adult at 18
  - If a MassHealth card doesn't come in the mail after a person is approved for SSI, call MassHealth.
  - If they ask you to complete a MassHealth application, ask to speak with a supervisor – tell the supervisor your adult child is on SSI
    - Completing a MassHealth application could cause problems; normally, people apply for MassHealth as adults at 19, but people on SSI should receive it automatically at 18.

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## The Big 4: SSI, SSDI, Section 8, MassHealth

### • Social Security Disability Insurance (SSDI)

- Based on the work history of the individual OR of the parent, if the person is a “Disabled Adult Child” (disability present before age 22)
  - If based on parent’s history, benefits begin when parent retires, becomes disabled, or dies
- May pay more than SSI (depending upon parent’s work history)
  - If it pays less, the person gets enough SSI to make up the difference
- No limit on savings, assets or unearned income, but the person can’t earn more than \$1,170/month (in 2017)

## The Big 4: SSI, SSDI, Section 8, MassHealth

### • SSDI and health insurance

- SSDI makes you eligible for Medicare after 2 years, NOT MassHealth (Medicaid)
- MassHealth is the main way to pay for long-term services and supports
- If the SSDI payment is above the MassHealth income limit, the person could lose their MassHealth
  - An exception: Won’t lose MassHealth if moving from SSI (as an adult) to SSDI is the only reason the income went too high
  - Don’t retire until your child is getting SSI as an adult, if you have a strong earning history

## The Big 4: SSI, SSDI, Section 8, MassHealth

### • SSDI and CommonHealth

- Those who lose MassHealth may qualify for CommonHealth; it can also be used to pay for long-term services and supports
- May need to pay a premium, based on income
- Qualify based on own income at 19
- Must meet one of the following to qualify:
  - Working 40 hours a month
  - Meeting a one-time deductible
    - Show medical expenses not covered by insurance in a 6 month period above a certain amount:  $(\text{Gross monthly income} - \$542) \times 6$
  - Being HIV positive and having a household income of 200% or less of the Federal Poverty Limit

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## Emergency Aid to the Elderly, Disabled, and Children (EAEDC): A cash benefit for those who don't qualify for SSI or SSDI

- Qualify if:
  - Disabled,
  - Caring for someone who is severely disabled,
  - 65 years old or older, or
  - Getting training from a Massachusetts Rehabilitation Commission program.
- Payment rates:
  - Single person with shelter costs: \$303.70
  - Each person in a married couple: \$202.50
  - Homeless: \$92.80
  - Rest home resident: \$72.80

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## The Big 4: SSI, SSDI, Section 8, MassHealth

### • Section 8 – a portable voucher

- 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 MassHealth benefits
- Can be a 10-12 year wait
- Can apply at 18
- May only have 60 days to use it, but can usually get an extension for a person with a disability (120 days total)
- A person with a disability can receive a two-bedroom voucher if they need an aide to live with them – but the aide cannot be a close family member (a cousin might be OK)
- Having a family member be the landlord can be permitted as a reasonable accommodation for disability, but the person renting must live in a legal, separate unit
- “18? Section 8!”: a video and website to help you through the process ([www.18section8.org](http://www.18section8.org))

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## The Big 4: SSI, SSDI, Section 8, MassHealth

### • Three ways to apply for Section 8

- The Centralized Waiting List
  - Apply online (<http://www.section8listmass.org/>)
  - Login annually to update application and make any changes to prevent being taken off the list
  - Make sure they have an up to date address
- The Department of Housing and Community Development (DHCD) Housing Choice Voucher Program (HCVP) Section 8 list (also called the regional non-profit list)
  - Fill out a paper application and mail it or hand carry it to the non-profit serving your area (Metropolitan Boston Housing Partnership serves Boston) (<http://www.mass.gov/hed/economic/eohed/dhcd/rental-applications-and-documentation.html>)
  - Contact them annually to update application and make any changes to prevent being taken off the list
  - Make sure they have an up to date address
- Housing authorities that have vouchers, but don't participate in the Centralized Waiting List
  - The list includes Boston and Cambridge
  - <http://18section8.org/wp-content/uploads/2017/04/Additional-sources-of-Section-8-vouchers2017.pdf>

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## Project-based Section 8

- Another type of Section 8
- The voucher belongs to a specific address and is NOT portable
- Waiting lists may be much shorter
- Living in project-based Section 8 for a year can move someone to the top of the portable Section 8 voucher waiting list
- A person with a disability can receive a two-bedroom voucher if they need an aide to live with them – but the aide cannot be a close family member

## The Big 4: SSI, SSDI, Section 8, MassHealth

- MassHealth ***is*** Medicaid
- Medicaid “State Plan Services” are the main way to pay for long-term services and supports
  - An entitlement, meaning there are no waiting lists
  - Both MassHealth Standard and CommonHealth members can use state plan services
  - State plan residential services include Group Adult Foster Care, Adult Foster (or Family) Care, and Personal Care Attendant services
  - May ***not*** be used to pay for housing
  - Follow events in Washington, D.C. – “block granting” or “capitation” of Medicaid would mean waiting lists for state plan services

## Group Adult Foster Care (GAFC)

- Available at age 22
- May be used in either subsidized housing or assisted living settings served by a GAFC organization
- Must need at least prompting with one or more activities of daily living (ADLs): toileting, bathing, dressing, eating, mobility, transferring in or out of a wheelchair
- Maximum 3 residents “per unit” (unit must have at least one bedroom and one bathroom)
- Funding worth \$14,720 per person per year (@ \$1,227/month)
- At least 1 caregiver per 10 residents
- Residents may not be aggressive or self-injurious
- “Emergency service” must be available 24/7
- Supposed to cover 14 hours per person per week.

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## Adult Foster Care (AFC)

- Available at 16
- A provider cares for up to three adults with disabilities either in the provider’s home or in the home of the person(s) with disabilities
  - The person with disabilities may need to pay room and board if the home belongs to the provider
  - If the provider lives in the home of the person with disabilities:
    - The stipend is tax-free only if the provider is paying rent
    - The provider must receive enough compensation to equal the minimum wage, with overtime over 40 hours/week (value of any free rent counts as pay; 5+ hours of continuous sleep don’t count as work) – may need 3 adults with disabilities to cover cost

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## Adult Foster Care (AFC) (2)

- Provider receives a tax-free stipend from Medicaid for 50 weeks
  - About \$9,125/year for Level I care<sup>1</sup>
  - About \$18,250/year for Level II care<sup>2</sup>
- If the **caregiver** qualifies for food stamps, the individual with a disability cannot also qualify for food stamps if the caregiver chooses not to count the individual as part of the caregiver's household
  - If the caregiver does not qualify for food stamps, the individual with a disability cannot receive food stamps.

<sup>1</sup> Needs at least prompts for one or more ADLs

<sup>2</sup> Needs physical assistance with three or more ADLs, or two ADLs plus a behavior

## Adult Family Care (AFC)

- Same as Adult Foster Care, but the caregiver is a family member who is not a legal guardian
  - Generally means a parent cannot be a caregiver until the individual is 18
  - Often at 18 one parent will become the guardian while another becomes the caregiver

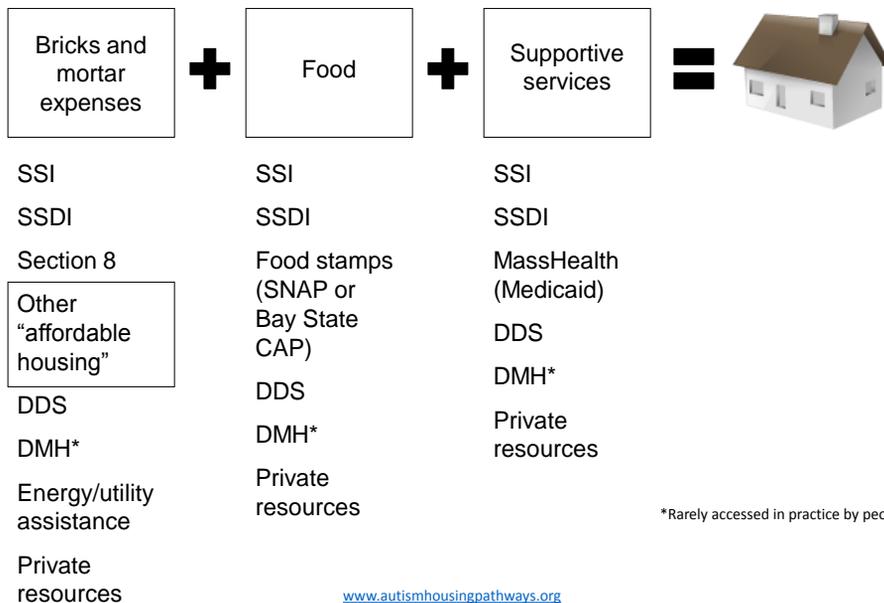
## Personal Care Attendants (PCA)

- Cannot be combined with Adult Family Care or Group Adult Foster Care
- Must need physical assistance with 2 or more ADLs
- A PCA cannot be a legal guardian; for adults, a parent who is not a guardian can be a PCA
- PCAs may only work the number of hours approved by MassHealth
- PCAs make \$14.56/hour; it will go to \$15/hour in July 2018
- A waiver is needed for PCAs who work over 40 hours/week for all clients
- If you need less than 15 hours/week of assistance, it may be more cost effective to apply for Adult Foster Care; if you need 24/7 coverage, it may also be preferable to apply for Adult Foster Care, as PCA only covers specific tasks for short periods of time
  - For people who consistently need assistance throughout the night (i.e. with a breathing tube, or nighttime toileting due to a prostate condition), overnight PCA might be a possibility

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## Funding streams



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## Other affordable housing

- Private affordable housing
  - Certain housing developers are required to offer affordable units due to tax credit deals or funding they received from MassHousing
  - Some units are reserved for clients of DDS and DMH
  - While cheaper than market rate, private affordable housing is generally not affordable to individuals living on SSI if the project is not participating in the project-based Sec. 8 program.
- State elderly housing
  - 13.5% of beds reserved for younger persons with disabilities
- MRVP and AHVP
  - These programs are similar to Sec.8, but run by the state. Frequently, the waiting lists are closed. More information is available at: <http://www.mass.gov/hed/housing/rental-assistance/mrv.html> and <http://www.mass.gov/hed/housing/rental-assistance/ahvp.html>

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## Other affordable housing (2)

- Affordable assisted living
  - The Mass. assisted living statute applies to those 22 and up with a disability
  - Individual may be eligible for SSI-G, which pays more, but cannot be combined with Sec. 8
- Single room occupancy is run by Caritas Communities. Homes are located on mass transit, and rent is generally about \$145 per week. A supervisor may be present.
- AHP's Housing Opportunities Available page has links to affordable and subsidized housing search engines:

<http://autismhousingpathways.org/services/housing-opportunities/#AffordableHousing>

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## Other affordable housing (3)

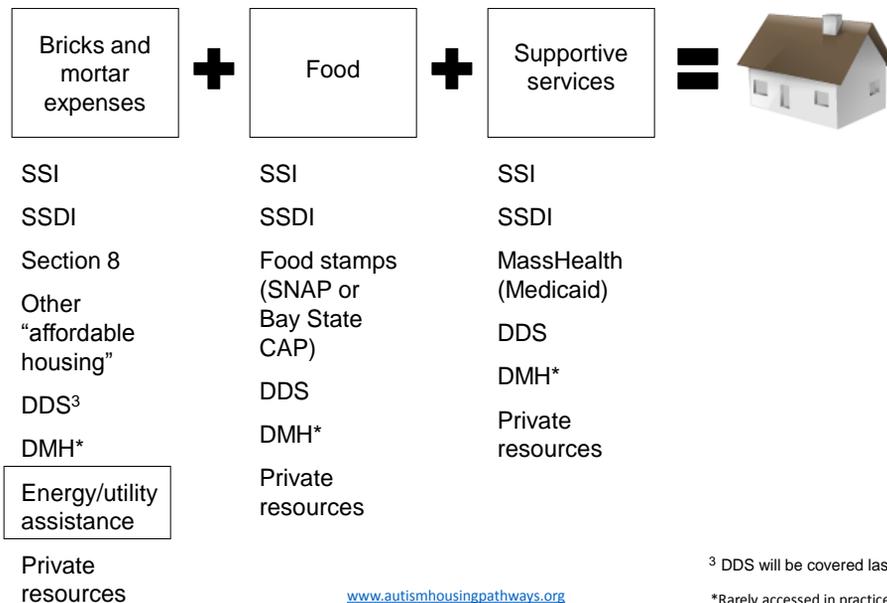
### • Rest homes

- While rather institutional, for some it may be a viable alternative to homelessness
- Unlike a nursing home, there are no restrictions on coming and going
- The Somerville Home is open to individuals 50 and over who need assistance with one or more activities of daily living
- Individual retains \$72.80/mo of SSI or EAEDC<sup>4</sup> check, turns the rest over to the rest home, and the balance of costs are paid by MassHealth.
- Private pay costs apply to those not on SSI or EAEDC.

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## Funding streams



<sup>3</sup> DDS will be covered last.

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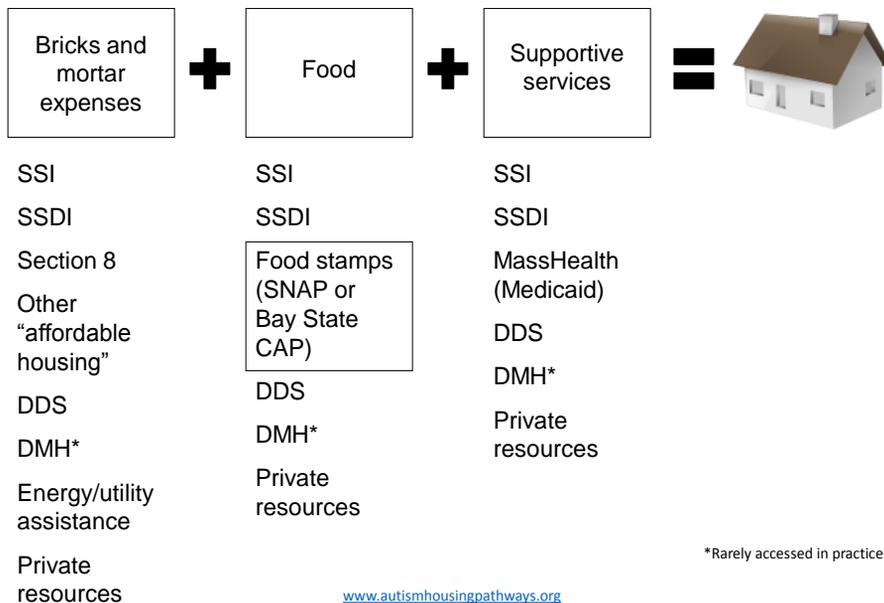
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## Energy/utility assistance

- Low Income Home Energy Assistance Program (LIHEAP)
  - Only if heat is not included in rent
    - LIHEAP payment goes directly to heating company (up to a cap set annually)
  - OR rent is more than 30% of income (an option before Section 8 kicks in)
    - LIHEAP pays portion of rent (up to 30%/month up to a cap set annually)
- Citizen’s Energy (Call JOE-4-OIL) and Distrigas heat assistance
  - After exhaust LIHEAP for the year
  - Voucher for one delivery of 100 gallons of home heating oil or \$150 natural gas credit
- Weatherization Assistance Program
  - Free weatherization for recipients of SSI or of LIHEAP
- Gas and electric subsidies<sup>4</sup>
  - 20%-40% discount
- Telephone subsidies<sup>5</sup>
  - A discount on local landline calls OR
  - Free cell phone with set number of minutes per month

<sup>4</sup> and <sup>5</sup> Bill must be in name of SSI recipient.

## Funding streams



\*Rarely accessed in practice by people with autism

## Food stamps

- Two kinds of food stamp programs:
  - SNAP (Supplemental Nutrition Assistance Program)
    - Pays \$200, less 30% net income (usually about \$100/month)
  - Bay State CAP (Combined Application Project)
    - Apply for when you apply for SSI, or can apply at the Social Security office if already receiving SSI
    - May pay more than SNAP (up to about \$150/mo)
    - Must buy and prepare food separately from others in household who don't get food stamps
    - Must have no earned income when you apply
    - May be better off with SNAP if
      - Your medical expenses exceed \$35/mo
      - You pay heating/cooling separately from rent
- Because of program constraints, not usually an option before 22 unless living independently

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## Housing program by immigration status

(Source: Mass. Law Reform Institute)

Status	State housing for families	State elderly/disabled housing	State-funded multi-family housing	MRVP and AHVP portable vouchers	Federal housing programs that permit immigrant applicants*	Other federal programs, including Section 8
US Citizen	eligible	eligible	eligible	eligible	eligible	eligible
Lawful permanent residents ("green card" holders)	eligible	eligible	eligible	eligible	eligible	eligible
Other "eligible non-citizens"+	eligible	eligible	eligible	eligible	eligible	eligible
All other immigration statuses, including undocumented	eligible	eligible	eligible	eligible	eligible	no

\* Some federal multifamily buildings; Housing Opportunities for Persons with AIDS (HOPWA); McKinney Homeless Programs (except for the McKinney Section 8 moderate rehabilitation program); Shelter Plus Care; Supportive Housing; HOME Rental Assistance; Low Income Housing Tax Credit properties (unless there are other housing program rules for the property to which immigration restrictions may apply)

+ A registry immigrant (admitted for permanent residence by the U.S. Attorney General and eligible for citizenship); a refugee or an asylee; a conditional entrant; a parolee; a withholding grantee; a person granted 1986 amnesty status; a resident of the Marshall Islands, Micronesia, Palau, or Guam; a victim of trafficking or relatives of such a victim; VAWA (Violence Against Women Act) Self Petitioners

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# Supportive services and cash benefits by immigration status

(Source: Mass. Law Reform Institute)

Status	DDS	MassHealth Standard*	CommonHealth*	SSI	SSDI	EAEDC	SNAP
US Citizen	eligible	eligible	eligible	eligible	eligible		eligible
Qualified resident AND not subject to a 5 year bar	eligible	eligible	eligible	may be eligible under certain conditions (see + below)	only if the individual has a SS# issued in 2004 or later authorizing work, has a B-1, D-1, or D-2 visa, and has paid into SSDI	eligible	eligible
Lawfully present (other than those covered in the previous line)	eligible	only pregnant women <200% FPL and children 1-20 <150% FPL	only disabled children (0-18) >150% FPL	may be eligible under certain conditions (see + below)	see above	eligible	children <18; disabled adults
Non-qualified PRUCOL	eligible	only pregnant women <200% FPL	only disabled children (0-18) OR disabled 19 & 20 year olds <150% FPL	no (unless receiving SSI or had pending application on 8/22/96)	see above	eligible	no (except certain battered immigrants, Cuban/ Haitian entrants, veterans in lawful status)
Undocumented	no	only pregnant women <200% FPL, or if on MassHealth since 1997	only if on MassHealth since 1997	no	no	no	no

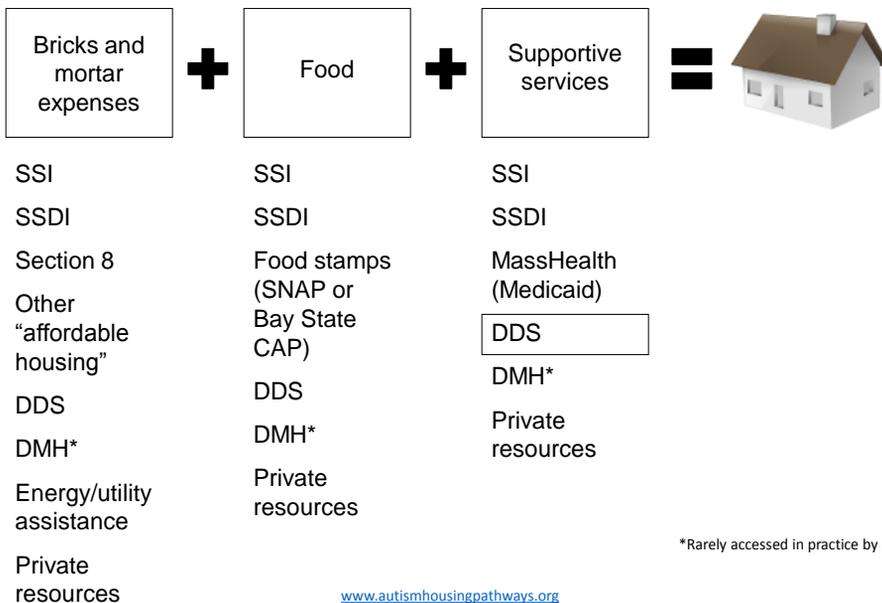
\* To have AFC, GAFC, PCA, or day habilitation covered, one must be on MassHealth or CommonHealth

+ <http://www.ssa.gov/ssi/spotlights/spot-non-citizens.htm>

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## Funding streams



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## What if I do get group home funding?

- Group home funding is based on rates created by Chapter 257\*
  - Per diem rates are based on program model (Basic, Intermediate, or Medical/Clinical), number of residents per house, and number of full time equivalent (FTE) direct care staff
    - Basic, 4 person house with 5.5 FTEs = \$249.39 per diem
    - Intermediate, 5 person with 12.7 FTEs = \$410.67 per diem
- Most are offered an empty bed with funding attached to it (a “funded vacancy”) in an existing house
  - If a vacancy is a poor fit, ask to see other options, including in other DDS area offices
  - Be aware that turning down more than one placement may make it difficult to get a placement until something substantive changes in your family situation

\* <http://www.mass.gov/eohhs/docs/eohhs/eohhs-regs/101-cmr-420.pdf>

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## What if I do get group home funding (2)?

- “Family-driven” housing
  - Some service providers give families more input into how a house is run, or work with families to create unique housing models
    - Example: a Chinese cultural home in West Roxbury
  - More likely to be newly opened homes
  - Since priority is not usually determined until shortly before turning 22, it is difficult to create a new out-of-the-box model at 22
    - May need to get into the system, then try to move around later

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## What if I do get group home funding (3)?

- Under a new policy\* DDS will not “license, fund or support new residential development” with any of the following characteristics:
  - Settings that have limited, if any, interaction with the broader community;
  - Settings that use or authorize restrictions that are used in institutional settings;
  - Farmsteads or disability-specific farm community;+
  - Gated or secured communities for people with disabilities;
  - Settings that are part of or adjacent to a residential school;
  - Multiple settings co-located and operationally-related that congregate a large number of people with disabilities for significant shared programming and staff; and
  - Multiple settings on a single site or in close proximity

\* <http://www.mass.gov/eohhs/gov/laws-regs/dds/policies/hcbs-policy-2014-1.pdf>

+ DDS is open to day programs involving farming and to a shared living situation on a farm, provided the person does not live on the farm where they spend their day.

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## DDS – Waivers

- An individual receiving services as an adult from DDS may apply for a waiver. The waiver is, technically, waiving the right to receive Medicaid services in an institution (e.g. Fernald), and opting to receive services in the community instead. Participants must be on MassHealth, and meet specific MassHealth waiver requirements.
- The state receives 50 cents back from Medicaid for every dollar it spends on waiver participants.
- The dollar value of services received under a waiver may be capped, as may the number of waivers available. When a waiver is full, someone must give up a waiver for someone else to get it.

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## DDS – Waivers (2)

- 3 types:
  - Intensive supports: need 24 hour supervision. May not be combined with GAFC, AFC, PCA. 8,970 served in 2014-15; no dollar cap.
  - Community living: need extensive supports to live on one's own or with family, but do not need 24 hour supervision. May not be combined with GAFC, AFC, PCA . 2,197served in 2014-15; \$70,000 cap (in 2016).
  - Adult supports: minimal supports needed; may be combined with GAFC, AFC, PCA. 2,893 served in 2014-15; \$40,000 cap (in 2016).

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## DDS – Waivers (3)

- Waiver services may be delivered in one of three ways:
  - Traditional service provider
  - Agency with choice
  - Fiscal intermediary
- Waivers services are portable; you may ask to change providers at any time.
- A waiver brief may be found at:  
<http://www.mass.gov/eohhs/docs/dmr/hcsis/hcbs-brief.pdf>
- A comprehensive waiver programs guide may be found at:  
<http://tinyurl.com/yakm2waf>

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## DDS – self-direction

- DDS has a program that allows individuals to self-direct their services, the Participant-Directed Program (PDP)
  - Do not need to be on a waiver to participate
  - <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/self-directed-supports.html>

## Developing a housing strategy: housing's effect on benefits

- Family provides a place to live without charging the individual (affects benefits)
- Family provides a place to live without charging fair share (affects benefits)
- Individual rents with help from family (affects benefits)
- Individual rents without family help (affects benefits)

## Developing a housing strategy: possible ways to control or acquire property\*

- Rent, using a voucher
- Convert basement or garage
- Add on an accessory apartment
- Sell home and buy two condos
- Sell home and buy a two or three family
  - Third unit might be for rental income or maybe two families buy together
- Individual can (if income is high enough to qualify for a mortgage) enter a first-time homebuyer lottery
- Buy a condo or house (either alone or with other families)

\* Nothing here constitutes legal, financial or real estate advice

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## Some possible housing strategies (1)\*

- Liam
  - Applies for an apartment in state senior housing and gets in after 3 years
  - Uses Group Adult Foster Care to pay for two hours a day of services
- Ana
  - Her parents give her a fixed amount every month, which she combines with her own funds to get an apartment in private affordable housing

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## Some possible housing strategies (2)\*

- Raj
  - Gets on the Section 8 waiting list at 18, and waits 10 years for a voucher
  - When Raj gets his voucher, his family uses a home equity loan to convert the garage to an apartment
  - Raj uses individual support hours from DDS

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## Some possible housing strategies (3)\*

- Bin
  - Gets on the Section 8 waiting list at 18, and waits 10 years for a voucher
  - While waiting, his mother is his Adult Family Care provider, and his father is his guardian
  - His mother saves some of the AFC stipend for 10 years, acquiring money for a security deposit, furniture, and appliances
  - When he gets his voucher, he moves into an apartment with two friends who also receive AFC
  - An Adult Foster Care provider moves in with Bin and his friends

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## Some possible housing strategies (4)\*

- Sue
  - Gets on the Section 8 waiting list at 18, and waits 10 years for a voucher
  - While waiting, her mother is her Adult Family Care provider, and her father is her guardian
  - Her mother saves the AFC stipend for 10 years, acquiring \$90,000 to use as a down payment
  - When she gets her voucher, her parents buy her a condo, and she uses the voucher to pay rent; her parents use the rent to pay the mortgage
  - An Adult Foster Care provider moves in with Sue
  - Sue's parents retire, and Sue moves onto SSDI, possibly increasing her income

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## Housing strategies should reflect a vision

- Person-centered planning
  - Method for your family member to plan a future based on their dreams
  - Relies on “circles of support” to carry out plans:
    - Circle 1: Those closest to the person
    - Circle 2: More distant friends and relatives
    - Circle 3: Acquaintances
    - Circle 4: People paid to be in their life
  - Ideally done with a facilitator, but some free tools are available:
    - “My interests, hopes, and dreams”: <http://pcp.sonoranucedd.fcm.arizona.edu/sites/pcp.sonoranucedd.fcm.arizona.edu/files/Preference%20Tool.pdf>
    - “Circles of support manual”: <http://bit.ly/2xBtLw0>
    - “One-page profiles”: <http://tinyurl.com/y79eyf3e>

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## Housing strategies should reflect a vision (2)

- Letter of intent
  - Statement by parents/guardians of intent for the person's future
    - Nitty-gritty information (doctors, medications, medical history, location of life insurance policy, will, etc.)
    - Family member's likes, dislikes, favorite places/activities/videos, etc.
    - "Footprints for the Future", a letter of intent form is available from Emarc at <http://bit.ly/2ygcdr2>
  - A living document: update it regularly
- Tend your child's circle of support like you would tend a garden
  - Have dinner once a year and update everyone
  - Invite the person your child would rely on most when you're gone to attend an IEP or ISP meeting

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## How do I develop assets?\*

- Do your best to save; ask close family if they can help
- Financial planning
  - Don't save money in your family member's name: they can lose eligibility for government benefits
  - Consider an ABLE account – it's a way to save for your family member without hurting their eligibility for government benefits: go to <http://www.fidelity.com/able/attainable/overview>
  - Individual Development Account
    - A way your family member can save for a home, and get matching funds
    - Participants must work (part-time counts), not own a home, and have household income below 200% of the federal poverty limit
    - Learn more at <http://midascollab.org/our-work/building-assets#matched>
    - Make sure the IDA program knows if your family member is on SSI or MassHealth, as it affects where the matching funds can come from

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## How do I develop assets? (2)\*

- If you are your family member's Adult Family Care provider, you might try to save some of the stipend
- Your family member might save earnings in an ABLE account
  - Full time students on SSI who work are allowed to earn more than usual, but they are not allowed to have more than \$2,000 in assets
  - Putting earnings in an ABLE account can allow a student to save for the future and still stay on SSI

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## Why are living skills so important?

- A recent study showed living skills is the single most important predictor of success for adults with autism\*
- About 40% of people with autism won't qualify for AFC, GAFC, or PCA, and some won't qualify for individual supports from DDS
  - In these cases, the more living skills someone has, the cheaper it is to support them

\* <https://www.autismspeaks.org/science/science-news/autism-study-associates-self-care-skills-success-adulthood>

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## What skills does my family member need?

- The Adolescent Autonomy Checklist is a great way to find out what skills to work on
  - <http://tinyurl.com/j95sycy>
  - Includes cooking, cleaning, public transit, filling out an application, etc.
  - Get ideas for IEP goals
  - Have your family member pick goals they would like to work on
- “Skills for living” on the AHP website: <http://autismhousingpathways.org/links/#Skills>
  - Links to apps and websites to help teach living skills or coach someone through tasks
- Centers for Independent Living
  - These Centers can help young people gain skills they need
  - Mentors may be available to help teach skills
  - <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory-results/MA>

\* <https://www.autismspeaks.org/science/science-news/autism-study-associates-self-care-skills-success-adulthood>

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## Where do I go from here?

- Work through the Turning 18 checklist
- Apply for housing
- Use “My Benefits Generator” to figure out the MassHealth supports for which your family member might be eligible: <http://mbg.neindex.org/>
- Develop a savings strategy
- Pursue options to improve your family member’s skills
- Download a housing workbook for your family member to complete: <http://autismhousingpathways.net/autism-housing-pathways-issues-housing-workbooks/>
- Work with your child to identify their circles of support, and complete a person-centered planning workbook
- Need an easy way to remember what you learned today? Check out <http://autismhousingpathways.org/housing-in-a-months-worth-of-tweets/>

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