Developing A Housing Strategy:
Because Mom and Dad Living Forever Isn't A Plan

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Part 1: Kids with autism grow up, and they need a place to live

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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 with autism live with parents or guardians
- 80 - 90% of adults with autism aren’t working

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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
- Develop a housing strategy that you can implement over time; 5-10 years is not uncommon
- Develop assets (before 18, if possible!)
  - Talk to a financial planner about ABLE accounts and special needs trusts.
- Develop your family member’s skills: http://bit.ly/1Nak9zm
- Consider assistive technology
- Use environmental design to improve outcomes and provide flexibility as funding streams and needs change
- Root your plan in a person-centered vision

* Nothing here constitutes legal, financial or real estate advice

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The housing equation

Bricks and mortar expenses + Food + Supportive services =

- 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 in Massachusetts

Bricks and mortar expenses	+	Food	+	Supportive services	=	

SSI

SSDI

Section 8

Other "affordable housing"

DDS

DMH*

Energy/utility assistance

Private resources

SSI

SSDI

Food stamps (SNAP or Bay State CAP)

DDS

DMH*

Private resources

SSI

SSDI

MassHealth (Medicaid)

DDS

DMH*

Private resources

* Rarely accessed in practice by people with autism.

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The Big 4: SSI, SSDI, Sec. 8, Medicaid

- SSI
  - Cash benefit of $735/month in 2017
    - 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

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The Big 4: SSI, SSDI, Sec. 8, Medicaid

- Sec. 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

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The Big 4: SSI, SSDI, Sec. 8, Medicaid

- 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

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Funding streams in Massachusetts

Bricks and mortar expenses	+	Food	+	Supportive services	=	

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		

* Rarely accessed in practice by people with autism.

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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

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Developing a housing strategy: possible ways to acquire property*

- Convert basement or garage (be aware of zoning)
- Add on an accessory apartment (be aware of zoning)
- Sell home and buy two condos
- Sell home and buy a two or three family
  - 3rd unit might be for rental income or 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) – Fannie Mae allows parents/guardians of adults with disabilities buying them a home to get a mortgage for as little as 5% down: https://www.fanniemae.com/content/guide/selling/b2/1/01.html

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Some possible Mass. 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 Mass. housing strategies (2)

- Raj
  - Gets on the Sec. 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 Mass. housing strategies (3)

- Sue
  - Gets on the Sec. 8 waiting list at 18, and waits 10 years for a voucher
  - While waiting, her mother is her Adult Family Care (AFC) 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, increasing her income

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Advocacy challenges

- Possible capitation/block granting of Medicaid under the AHCA/BCRA
  - The CBO estimated a reduction in projected federal Medicaid outlays of $834 billion over 10 years under the AHCA (also reflects elimination of Medicaid expansion)
  - States may choose to eliminate or reduce optional programs (including certain Medicaid waivers and state plan services) to adjust to reduced federal funding
- Proposed budget cuts to SSDI and SSI
  - The Arc estimates 946K could lose SSDI and 2.1 million could lose SSI
- Proposed budget cuts to HUD
  - 22% overall cut including a 5% cut to Section 8 HCVP (mobile vouchers) and a 17% cut to Sec. 811 housing for people with disabilities (another HUD program)
- State and local zoning that limit accessory units, granny pods, and tiny houses

Skill development IS part of your housing strategy!

- A recent study showed adaptive living skills is the single most important predictor of success for adults with autism*
  - The more skills, the cheaper the staffing costs
- Adolescent Autonomy Checklist: http://tinyurl.com/j95sycy
- Consider assistive technology to initiate or coach someone through tasks: http://mahousingthinktank.org/technology/
- "Skills for living" on the AHP website: click on "Links"
- Centers for Independent Living:
  - http://www.ilru.org/projects/cil-net/cil-center-and-association-directory

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

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You can improve outcomes by modifying the living environment

- A living space that is designed with autism in mind is trigger-free, sensory friendly, predictable, stands up to wear and tear, and provides private spaces to retreat
- Such an environment can:
  - Reduce anxiety
  - Increase independence
  - Reduce conflict with landlords and neighbors
  - Reduce repair and staffing costs
- Consider a housing design that can adapt to changing regulatory environments and support needs: http://tinyurl.com/y742cbsv
- Learn more:

  http://mahousingthinktank.org/autism-friendly-design/

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Where do I go from here?

- Apply for Section 8 if any waiting list near you is open
- Find out what State Plan HCBS services (1915i) exist in your state
- Investigate local zoning
- Develop a savings strategy that will not affect your family member's benefits: consult a financial planner and look into ABLE accounts: http://www.ablenrc.org/
- Pursue options to improve your family member's living skills, and get them used to looking to someone other than Mom and Dad for support
- Identify assistive technology and design elements that might reduce costs and improve outcomes
- Download a free housing workbook for your family member from our website
- Find your peeps: fellow families, a lawyer, a financial advisor, a life coach, a property manager (you get the idea)
- Use person-centered planning to develop a vision and map out a housing strategy

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Part 2: Person-Centered Planning
What, Who, Why, and How

Cheryl Ryan Chan, Principle Facilitator

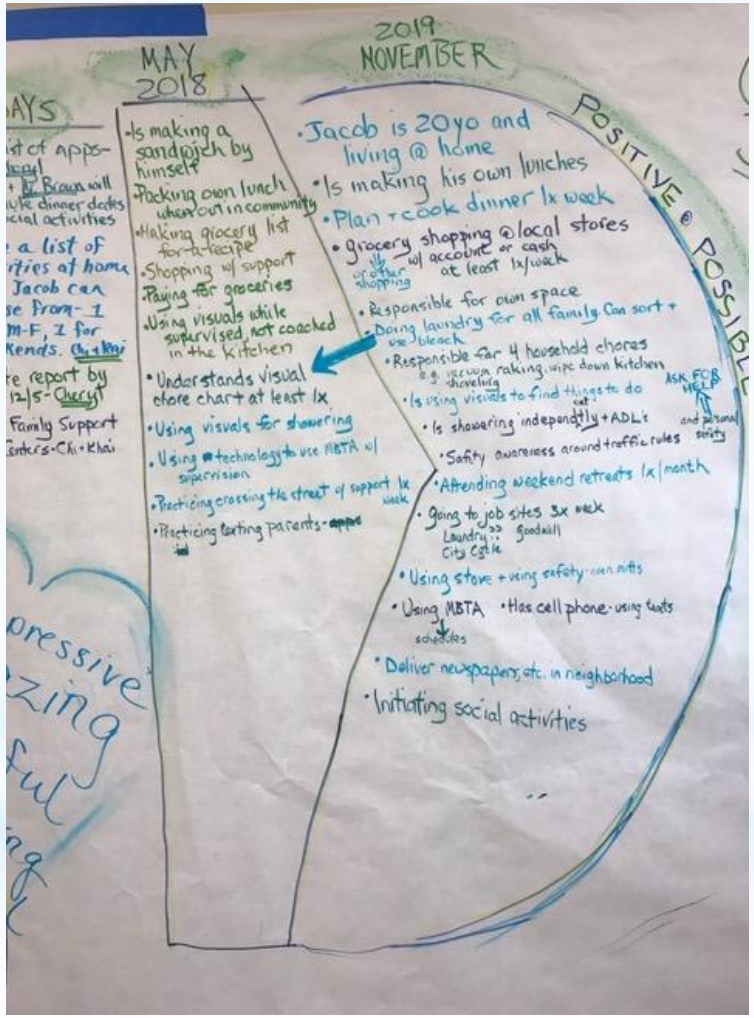
Demystifying *plans* vs. *practices*

Person-Centered "practices" and "approaches" and "thinking" are relatively similar descriptions of philosophies and techniques that can be applied to the behaviors and tools that organizations and systems providers use when employing person-centeredness to what they are already doing.

Person-Centered "planning" is a methodology that is used to guide a person and their Circle of Support through the identification of what, who, when, and how a person's future can be developed BASED ON (AND HONORING THROUGHOUT) their highest dreams, desires, gifts and contributions they can bring to their own communities.

Essential Elements of a PCP

- Setting the stage & ground rules
- Commitment
- The Dream & the Gifts
- Positive & Possible Goals
- Checking in Halfway
- Circle of Support
- Planning for Sustainability



- people committed to each other & their roles
- the absence of a hierarchy among participants
- attentive listeners without distraction or agendas other than the process
- skilled facilitators not bound by systems limitations

Essential Elements of a PCP: the Circle of Support

- The most difficult but among the most essential elements of PCP:
- Requires opening ourselves up to inviting others to become an intimate part of our loved one's life
- Requires us to be vulnerable, to be open to hearing opinions and allowing others to assume roles in their life.

> *Remember, we all stumble, every one of us. That's why it's a comfort to go hand in hand.*
>
> Emily Kimbrough

- Creates a natural and sustainable group of people who are invested and committed to your loved one
- Fosters deeper relationships that every person needs and desires
- Reduces the stress of the entire caregiving load on 1 person alone.
- Helps caregivers feel more at peace with their own mortality

Who it's for

Expecting a transition in the future (1-5 years).

Examples: transitioning out of school or supported environments (group home, mental health units/psychiatric care) changing home or employment situations, marriage/divorce, aging into supported living.

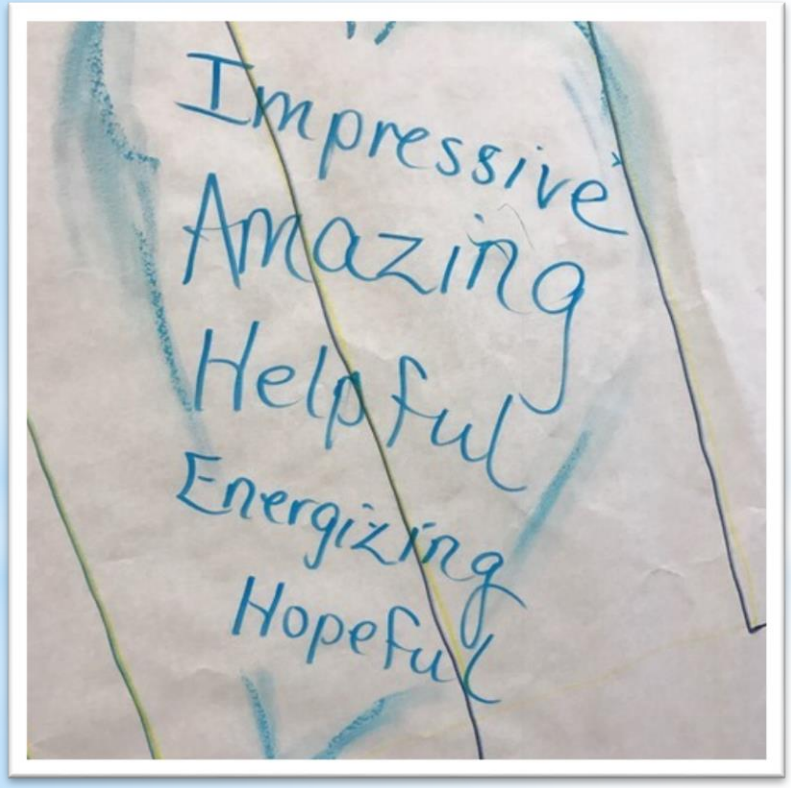
No specific transition, but seeking a new way to introduce themselves and communicate what's important to and important for them.

Why do a PCP?

We are the stewards of our own humanity and for those who cannot stand for their own.

- Self confidence improves
- Greater clarity & focus for school & support systems
- Development of new relationships
- Better & more sustainable outcomes
- Reduction of isolation & dependence on systems

How PCP integrates into a service plan



- Individuals and families are taking their plans and revamping their service plan goals to reflect their plan's positive and possible goals, and to work toward skill building and resource acquisitions that are true to the "real" future they anticipate.
- School teams are participating and finding the plans very helpful in their decision-making process. By having clearer pictures of the person's identity (visa vie the gifts), goals, natural supports and life outside of school hours, they can make more informed decisions and strengthen outcomes that apply to all environments.
- State providers and other systems folks are participating. After a recent plan was complete, a State-level autism services manager said "I don't understand why this isn't being done right now for every student in transition!"

FAQs and how to learn more

- Research your local resources; ask your State services departments, ARC offices, disability resource centers or do a basic internet search. There is no current nationwide directory of PCP facilitators or organizations.
- Facilitators should be independent of any state or regional service systems, agency or service provider or school representative who is actively supporting your loved one.
- Costs should be comparable to the average independent evaluation (educational, diagnostic, etc.)
- The plan process should include a minimum of 3 meetings over the course of 7-10 weeks, reports and recommendations from each meeting. Facilitators should conduct the meetings in your community, not theirs.
- Facilitators should encourage you to include a wide range of participants to create or continue the development of a Circle of Support.
- People with communication challenges CAN participate in person-centered plans! Skilled facilitators use their training to help everyone find their voice.

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