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

The young adults are 19-30 year olds. The figure is from a study done by Easter Seals in 2008.
Most families will need to face the challenge of finding or creating housing
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](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

Housing equation: Rules govern which government programs can be combined, which can’t, what they can be used for and where.

Developing a housing strategy:

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!

Asset development is beyond the scope of this talk, but it is crucial.

Cheryl will talk about the person-centered vision; I’ll talk about nuts and bolts.
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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As you can see, there is a range of government programs that your family member may be able to tap into, in addition to personal resources. All of them have rules about where they can be used, what they can be used for, and what other funding sources they can be combined with. Note that sources on this chart only appear under the kind of expense for which they can be used. For instance, Medicaid funds cannot be used to pay for bricks and mortar expenses.
### The Big 4: SSI, SSDI, Sec. 8, Medicaid

<table>
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<tr>
<th><strong>SSI</strong></th>
<th><strong>Cash benefit of $735/month in 2017</strong></th>
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<td><strong>Some states supplement this</strong></td>
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<td><strong>Benefit may be reduced, based on income from other sources</strong></td>
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<td><strong>Makes you eligible for Medicaid (pays for long-term services and supports)</strong></td>
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<td><strong>Can be used for housing or services; has income and asset limits</strong></td>
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<td><strong>SSDI</strong></td>
<td><strong>Based on the work history of the parent or of the individual</strong></td>
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<td><strong>If based on parent’s history, kicks in when parent retires, becomes disabled, or dies</strong></td>
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<td><strong>Usually pays more than SSI</strong></td>
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<td><strong>Makes you eligible for Medicare (does NOT pay for long-term services and supports)</strong></td>
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<td><strong>Can be used for housing or services; has fewer income, asset limits</strong></td>
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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 $735/month, 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).

If your family member receives SSI as an adult at 18, he or she is automatically eligible for Medicaid.

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: $1,170/month in 2017. The bad news is that SSDI doesn’t automatically make you eligible for Medicaid, while SSI does.

SSDI makes you eligible for Medicare after 2 years, but you cannot use Medicare to access certain critical long-term services and supports funded through Medicaid. That’s why it’s very important, if you have any control over the situation, to not retire until your child is getting SSI.
benefits as an adult. If you retire before your child is 18, your child is going to get SSDI and will never receive SSI as an adult – with one exception: if the SSDI benefit allocated to the child is less than the SSI benefit would be, SSI will make up the difference. (A footnote about SSDI: SSDI is not reduced for the spouse of a disabled person, if that spouse is caring for an adult child with a disability.)

Please note that if an individual moves from SSI to SSDI they cannot lose their Medicaid if that is the only reason their income now exceeds the cap for Medicaid eligibility.

In Massachusetts, it is still possible to access long-term services and supports if a person has only ever received SSDI, and that way is CommonHealth. This is aimed at people with disabilities who work or who meet a one time deductible. There may be similar programs in other states.
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](http://affordablehousingonline.com/open-section-8-waiting-lists)

The wait for a housing voucher is the primary limitation driving the ten year time clock for implementing a housing strategy.
Medicaid (MassHealth) 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, Medicaid HCBS waivers have caps on the number of people who can receive them, and frequently have waiting lists. Medicaid state plan HCBS services, by contrast, are an entitlement, meaning if you qualify for it, you have to receive it, and there can’t be a waiting list. 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.

A complicating feature is new regulations from the U.S. Department of Labor that require home caregivers receive the equivalent of minimum wage, with overtime after 40 hours. With live-in caregivers this presents an economic challenge. Fortunately, hours spent sleeping do not count toward the total (provided the caregiver can sleep through the night), and the value of free rent counts toward the total compensation. Nonetheless, it may well be necessary for individuals to share support costs with housemates to make using state plan services for live-in care financially feasible.
I want to come back to the “Funding Streams” slide to cover a few programs we haven’t talked about.

Other “affordable housing” can take many forms. One example in Massachusetts is state-run elderly housing, which reserves 13.5% of its units for younger adults with disabilities. Again, you can request a two-bedroom unit if an aid is necessary.

There are also other forms of affordable housing. Examples include local housing projects, Single Room Occupancy housing where individuals have their own locked room, but bathrooms and cooking facilities are shared, and private affordable housing. Private affordable housing includes situations where developers who received government tax credits need to provide a percentage of apartments at a reduced rent. This rent is usually too high for someone on SSI to afford. However, if a family member provides a regular stipend to the individual, it may be enough to make it work. Please note, a form guaranteeing the stipend will need to be submitted to the landlord, and the stipend will result in a reduced SSI benefit. Lower rents have also been created in instances where a property has been bought with a high down payment, making it possible to charge less in rent. An example is Hope House in Virginia. Let’s take a quick look at some ways to find other affordable housing; please note this is not a comprehensive list.

Food stamp payments vary wildly, from about $16/month to $194/month. As a practical matter, food stamps generally cannot be combined with any kind of foster care program, such as Massachusetts’ Adult Foster Care or Adult Family Care.
Energy and utility assistance can be worth about a thousand a year, but unless the utility bill is in the name of the individual with the disability, it’s really, really hard to access.

The other thing that’s worth mentioning is eligibility for a free cell phone. SafeLink is an example of a provider. If it’s for an individual with a disability or the elderly and you can show there’s a safety reason for it, you can get a free cell phone with a limited number of minutes per month on it. There can only be one per household.

State Developmental Disabilities agencies may have some form of individual supports for people who have their own place to live outside the family home, and who do not require 24/7 supports. In Massachusetts, this includes individual support hours, which may be combined with state plan services, so long as they do not result in duplication of care. For instance, an Adult Foster Care provider is responsible for overseeing showering, eating, etc., but individual support hours are used for things like skill building and community outings. In New Jersey, possible individual supports include a personal emergency response system.

In general, those who need 24/7 supports will need a Medicaid waiver administered by the state DD agency. In most states, this means a multi-year wait. In Massachusetts, a health and safety criteria is in place. This means the individual will not be prioritized for 24/7 supports so long as they can be kept healthy and safe in the family home. Once considered a Priority 1, an individual is supposed to receive supports within 90 days.
Finding “other affordable housing”

- State Housing Finance Agencies: [https://www.ncsha.org/housing-help](https://www.ncsha.org/housing-help)

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.
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](https://www.fanniemae.com/content/guide/selling/b2/1/01.html)

* Nothing here constitutes legal, financial or real estate advice
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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Group Adult Foster Care is a HCBS State Plan service in Mass.
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

AHCA: Individual allocations would be capitated, based on 2016 outlays. There would be an annual adjustment based on the Medical Consumer Price Index, with an additional 1% per year for the elderly and disabled. Block granting could be chosen by states for those who are not aged or disabled.

The president’s proposed budget assumes another $610 billion reduction in federal Medicaid outlays, due to states spending less than caps would allow.

“Based off of numbers from the Congressional Budget Office, The Arc estimates that about 946,000 SSDI beneficiaries could be kicked off of the program or be prevented from eligibility. They estimate that roughly 2.1 million people could lose access to SSI.”

A positive model exists in Rhode Island, where one bedroom accessory units are a reasonable accommodation for disability for owner-occupied homes, where the goal is to house a family member with a disability. In Mass., a bill is pending that would permit two-bedroom accessory units (to allow for a caregiver), with it permissible for the title to pass to a special needs trust.
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:


For those who don’t qualify for Medicaid State Plan HCBS services, or who live in states where there are no such services, the more skills the better. Hiring somebody to do things for your family member costs money, and the more things they can do independently, the cheaper it’s going to be.

The Adolescent Autonomy Checklist is a great resource for coming up with IEP goals. It’s basically a list of things your family member needs to know how to do when he or she goes forth into the world. It covers everything from making coffee to flipping a circuit breaker back on.

Assistive technology will be increasingly important, due to funding cuts and staffing shortages. Technology is becoming more powerful. An overview is available at Mahousingthinktank.org. Examples include an app to prompt someone through decision making, and a dedicated tablet that can provide a schedule with reminders, directions, a web-interface viewable by family or a case manager, and the ability to send texts to family or a case manager in case something fails to occur or there is a medical issue.

AHP has links on its website to information to help you identify, teach, and cue living skills.

The Centers for Independent Living help young people and adults with disabilities gain skills they need. Frequently a slightly older mentor with a disability works with an individual.
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](http://tinyurl.com/y742cbsv)

Examples of modifications include: no fluorescent lights, soundproof bedrooms, shatter resistant film on glass, bead board paneling, bathroom floor drains or waterproof membranes, water cut-off sensors, built-in shelving in place of bureaus, ensuite bathrooms. Spaces with clearly designed functions, sensory spaces, and transitional spaces that permit observation of common areas are all helpful.

I am talking about something I call configurable housing. An example would be a five bedroom dwelling unit that can be configured as a three bedroom with an attached au pair suit, and an attached one bedroom accessory apartment. The wall between the au pair suite and the accessory unit can be easily opened up, and a fire door closed between the au pair suite and the main house. Such a space could be easily reconfigured to meet a variety of needs. Examples are a 5 bedroom group home; a 4 bedroom group home with a live-in staff apartment; a home where parents can live in an in-law apartment, an Adult Foster Care caregiver in an au pair suite, and 3 individuals with autism occupy upstairs bedrooms; or a home where a shared living family occupies the upstairs bedrooms, an autistic individual lives in the au pair suite, and the accessory apartment might be rented to a tenant or occupied by a person with autism who just needs occasional assistance. A smaller scale example would be a three bedroom variation, with a master suite, an au pair suite, and an accessory one bedroom apartment. A schematic of the 5 bedroom is included in a presentation at this URL: [http://tinyurl.com/y742cbsv](http://tinyurl.com/y742cbsv)
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.ablenr.org/](http://www.ablenr.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

It is important that the individual get used to asking someone other than Mom or Dad for help. We have seen older individuals refuse to take help from anyone else (including siblings) when parents in their 70s are trying to pass the baton. At that point, it is partly ingrained habit, and partly connected with fear of facing life without parents.

Cheryl will talk about Circles of Support, which will flesh this idea out further. But I’ve mentioned certain roles that are crucial where housing is concerned.
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The title of our presentation is developing a Housing strategy – Cathy has just given you a lot of information to think about when it comes to housing options. We both speak regularly in Massachusetts, and what we are doing today is trying to condense what is usually about 2 hours each into 30 minutes each; thank God for technology and the rewind button!

So you’ve heard about what it takes to create the brick and mortar. The subtitle of our presentation today is “Because Mom and Dad living forever isn’t an option.” Cathy and I know that strikes a cord. We’ve heard it said more times than we can count in all the presentations and consulting that we’ve done over the years. Oddly, we haven’t found anyone yet who that’s worked for.

That statement is derived from our fears of our loved one being alone, abused, neglected, unloved, and uncared for. That’s a very realistic fear, when we do nothing. Just like the things that Cathy outlined as action items for pursuing and securing housing, preparing our family members for a dignified and happy life takes work! It takes years of hard work, it takes both physical and emotional stamina and advocacy. The greatest tool we have right now to guide this part of our journey is person-centered planning.
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.

Person-centered planning is a term that is often misused; it’s used as a catch-phrase or an adjective to describe an organization’s actions or intent. Let’s take a second to clarify what some of these terms actually mean <read>.
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
I want to dive a little deeper into the element of the Circle of Support, because it is the most difficult piece of a person-centered plan. <read>

Identifying, creating & sustaining a Circle takes work for a person with disabilities, and it doesn’t happen overnight.

We often hear “we don’t have a support system” or “my loved one doesn’t have any friends other than his family.” That’s not unusual, and it doesn’t mean a plan can’t take place. If a circle of support only includes intimate family members, then we will make expanding the person’s Circle part of the plan for the next 2-5 years, then how the circle can be sustained and stay fluid.

It’s vital that parents and caregivers understand that a Circle of Support is for the focus person, NOT for them. It also helps to remember that we all have COS, and we all need them. By changing their perspective in this way, it might become more clear why it’s critical and it may make the work a little easier.
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.

People who participate in PCPs often come to us after and say “I need one of these done for myself!”

The origin of PCP goes back to the 70s when de-institutionalization began for people with disabilities and other disadvantaged populations, but the methodology is so sound that it truly is applicable to anyone! PCP has the greatest value to a person who is expecting a transition in their lives in the next 1-5 years. There are also PCP processes that can support a person who may be “stuck” – that is, finding difficulty in communicating their own desires and goals, or manifesting their gifts and skills in their lives in ways that are meaningful. Circles of Support are then called upon to remind a person of their dreams and gifts, to become more familiar with the people they are supporting, and to enroll actively in the person’s life in ways that are valuable.
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

In the absence of a PCP, the systems take on the role of decisionmaking, and base those decisions on dollar amounts, data, bed space, functionality as determined by a “professional evaluator” and other impersonal determinants.

We all need to steward the humanity of those we love and those we support. PCPs ensure that the human factor is not just considered, but placed first and foremost, and that the planning discussion focuses on the gifts, contributions and voice of the person.
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 (via 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!”

This is the most important question we have to address when we are presenting the topic of Person-Centered Planning. There MUST be a connection to the systems supports; there must be a way to translate and apply a plan to a person’s life when the person is receiving funding and programming – whether it’s school or adult services, the system supports have a direct impact on quality of life, every day.

Families are often worried about how teams will respond and react when they are presented with a person-centered plan. Here’s the truth; they are loving it! More than 90% of the time, systems team members are participating in the plan process themselves; there has been no better way to convince them that this is an indispensible tool to the transition process in particular. The plans are driving the conversations and contributing to the creation of highly effective individualized service plans.
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.

FAQs and how to learn more