

3LPLACE



# TRANSITION TOOLS & TIPS

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# CONTENTS



---

**03**  
INTRODUCTION

---

**09**  
AGE 14

---

**11**  
AGE 15 TO 16

---

**13**  
AGE 17

---

**15**  
AGE 18

---

**18**  
AGE 19 - 22

---

**22**  
AFTER 22



# INTRODUCTION

## Congratulations!

If you're thinking about transition, you've already made it through the early years of special education. Nothing you will encounter in this guide is more challenging than what you've already accomplished!

Our goal here is to provide a quick-reference, chronological guide to the transition years for families living in Massachusetts. We'll be updating it annually to make sure information is current and that links work. ***If you find a broken link, please let us know; [you can email us here.](#)***

As you go, you can look for these arrows:



They highlight some of the most important tips and milestones along the way.







*The single most important thing to remember as you approach transition is that services to your young adult are not guaranteed after age 22.*



Until age 22, they are under the protection of the Individuals with Disabilities Education Act, and the Individualized Education Plan (IEP) **entitles** them to receive services through their school. After age 22, services are provided through a state agency which will determine their eligibility based on the information you provide. So: **Transition time is when you set the building blocks in place for the supports that will help them for their adult life.**

Think about it this way: You have been on a **school track** so far, working through your child's IEP team. Now, you need to run on both a school track and a **transition track** at the same time, in parallel, so there can be a smoother switchover when your child reaches 22.





## A FEW STRATEGIES:

- Keep it person-centered. Involve your family member in these decisions; it's about them and their life going forward. They have the right to self-determination (more about that on [this website](#)). You might consider entering into [a formal person-centered planning process](#). Many studies have shown that the degree of involvement a person has in the transition process predicts how happy and satisfied they will be with life after school. The [LifeCourse Framework](#) offers wonderful tools for person-centered whole life planning.
- What communications strategies will allow you to involve your young adult in making decisions about their life? Do you need to expand your library of visual aids? Consider new communication techniques that can help them overcome any barriers to getting their hopes and dreams across. For some people, this might involve calming techniques, while for others, it might require a dedicated Ipad, or other augmented communication device.
- Organization: set up calendars for major dates. Back up your materials, keep important documents in a safe, accessible place, preferably in digital format. Set aside a dedicated time several times a year to review and address the status of any paperwork needs.



- **HAVE A BACKUP PLAN AND PROVIDER:**

Identify a trusted person younger than you and in good health. This person does not have to be the same person who will take care of your family member if you are unable to, they just have to agree to hold this file in case it's needed. Give this person a self-contained file of important information and copies of important documents. Update this file annually.

*This is easier if you have a shared secure digital folder with this information that you can update regularly and remotely. It should include:*



- the most recent IEP or Individual Support Plan
- copy of birth certificate, passport and other identification
- the most recent neuropsychological and other evaluations
- contact information for medical providers with a description of the issue that brought you to them if they are a specialist
- a copy of, or the location of, your will. Any plans for ongoing care, such as the identity and contact information for a person who has agreed to assume responsibility in your absence
- tips on communication and behavioral strategies
- contact information for your young adult's social network (don't forget online communities)
- list of current medicines and therapies
- any food sensitivities and preferences
- Life Map or Person-Centered Plan
- and, anything else needed to continue your family member's life and care.



- **Think for the long haul, but don't let that overwhelm you.** Your young adult will change significantly over the years ahead. Think first about the life they want to lead before making long term decisions about where they will live. Think long term but be flexible as they adapt to new places and people in their lives. Don't commit to capital investments such as a property purchase before your young adult has settled into a lifestyle (day activities, work, social circles, recreation) that is meaningful and sustainable.
- **Learn the lingo.** There's a bewildering jungle of abbreviations, acronyms, and just plain jargon. There's also a whole new set of laws, rules and regulations to unpack. It is okay to keep a cheat sheet available and always speak up or Google anything that is unclear. These primers specific to Massachusetts may be helpful:
  - [Intellectual or developmental disabilities](#)
  - [Vision impairment or blindness](#)
  - [Mental health and mental illness](#)
- **Consider yourself** as you go through this list: Ask yourself: Do I need help? For which parts? The answers will help you decide whether to hire an advocate, an attorney, a transition planner, or if your family and team can manage it on your own. If your young adult has autism, there's help available from the state's [Autism Support Centers.](#)



# WE WANT TO SAY A WORD ABOUT OUR SOURCES.

We've quoted liberally from them because what they present is really good, and thorough. Our goal here is to organize the wealth of available information in a chronological format, because that's what we wished we'd had when we went through this with our own children.

***Most helpful to us, and we suspect also to you, are the following guides, all of which are available online.***

***We've provided links:***

Federation for Children with Special Needs [transition brochures](#), which provide an array of helpful flyers on the transition process, covering important topics such as graduation options, decision-making, autism, transition planning, employment, and more.

[Autism and the Transition to Adulthood Tool Kit](#), also comprehensive, published by Autism Speaks.

[Turning 18 Checklist](#), published by Autism Housing Pathways. This list focuses on housing needs, but contains other important tips and dates.

The [LifeCourse Nexus](#), is a framework developed by the University of Missouri and endorsed by both the Massachusetts Department of Developmental Services and the Massachusetts ARC, "to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live." Here's a video that explains it

[Transition Planning by Age](#), a great timeline from the ARC of Greater Haverhill and Newburyport. This list includes important age markers for encouraging the development of specific life skills. Each person is unique, so you will want to view these through your own parental lens. Here's the timeline in a [single page printable format](#).

[A Transition Guide to Postsecondary Education](#) and Employment issued by the federal Department of Education, while not specific to Massachusetts, contains a useful glossary at the end. Additionally, here's a [glossary](#) with definitions of different types of adult services in Massachusetts..

At the end of this guide, on Page 26, there's a helpful checklist that lets you quickly scan through for tasks you've covered, still need to do, or might want to think about.





## AGE 14 TO DO:

- ✓ **IEP Transition Planning** begins at age 14 with a school team transition meeting and the addition of a [\*\*\*transition planning form\*\*\*](#) to your child's IEP. This form, required by law, must be updated annually and is included with all IEPs between 14 and 22. In conjunction with this, the school will assess your young adult's likely future needs and supports, including training, further education, employment, and independent living skills. Here's a [\*\*\*discussion\*\*\*](#) of what should be in the plan.

This important transition process should:

- Provide the opportunity to learn self-determination skills.
  - Conduct person-centered planning with family and friends (see LifeCourse Nexus, below)
  - Develop post-secondary vision based on needs, preferences, and interests.
  - Identify disability related needs around each individual's goals and preferences.
  - Develop an action plan based on desired outcomes for adult living, postsecondary education, and employment.
  - Integrate transition needs and activities into the IEP goals, objectives/benchmarks, and services if appropriate for the student.
- ✓ **Review [\*\*\*this fact sheet\*\*\*](#)** from The Autism Program at Boston Medical Center for more guidance about what schools are required to do during the transition years, which begin now and continue until graduation or age 22.
  - ✓ **Apply for a [\*\*\*non-driver's identification card\*\*\*](#).** This is a permanent, official government-issued ID card, useful for many purposes. You must be at least 14 to apply.
  - ✓ **Review the [\*\*\*LifeCourse Nexus\*\*\*](#),** a strategy for whole life planning for people with developmental challenges. This is a comprehensive framework that can be accessed free of charge, and it will grow with your family member through various stages of life.



## AGE 14 THINGS TO THINK ABOUT:

- Am I going to need help with this?** If the terminology is unfamiliar and the paperwork and deadlines feel overwhelming, *consider a special education advocate.*
  
- Who else should be on our transition team?** Identify respected and trusted family members, friends, helpers, clinicians and others who can contribute to planning and/or provide continuity after transition.
  
- How are we going to pay for services after age 18? Age 22?** You might want to consult an attorney or a special needs financial planner, who can advise you on savings and investment plans, estate planning, and also about benefits that might be available to your family.





## AGES 15-16 TO DO:

- ✓ **Reread the section above, and consider whether you might have missed something.**
- ✓ **Update the document file you've given your trusted document keeper.**
- ✓ **Update the Transition Planning form** with any changes in plans, needs or preferences, and with an eye toward the transition assessments that were completed last year. If assessments weren't done, are outdated, or were inadequate, advocate for new ones.



*Remember, you want to be sure that Transition goals are linked to IEP goals, so learning in school provides the skills needed for later life in the community.*

- ✓ **Referral to an adult agency:** Your public school district must submit a "Chapter 688 referral" to the appropriate adult service agency at least two years before the date your child is expected to graduate, or when they age out of services at 22. So this event could happen as early as 15, depending on your child's birthday and school progress, or as late as 20. **Advocate with your school district to be sure this happens. If it hasn't you should send in an application on your child's behalf to the appropriate adult agency or agencies.**
- ✓ **Adult agency referrals** in Massachusetts can include the **Department of Developmental Services (DDS)**, the **Department of Mental Health (DMH)**, the **Commission for the Blind, the Commission for the Deaf and Hard of Hearing**, and the **Massachusetts Rehabilitation Commission (MRC)**. You will have options that include self-directing your care plan or choosing from a more traditional agency model. There is more about that below, please see Age 18. **[Here are some resources](#)** that might help you decide what adult services might be appropriate for your family.



## AGES 15-16 THINGS TO THINK ABOUT:

- ✓ **What funding is likely to be available to my family for post-22 services?** We'll point again to [an interactive benefits calculator](#) that might help. It's a good idea to consult it annually as situations, needs and available benefits are constantly changing. Remember to consider what services might be covered by your health insurance. You can find a series of fact sheets [here](#) about insurance benefits for individuals with autism. One note: be sure to look at the age provisions carefully as some services have a sunset; Applied Behavioral Analysis, for example, isn't covered by MassHealth after age 19.
  
- ✓ **Is work an option?** Massachusetts allows people to work under child labor guidelines as early as 14. If work is in the future, and that's articulated in your IEP, your school is likely to make a referral to the Massachusetts Rehabilitation Commission (MRC), which can provide training and support. Here's a [helpful graphic](#) about the path to support from MRC





## AGE 17 TO DO:

- ✓ **Reread the sections above, and consider whether you might have missed something.**
- ✓ **Update the document file you've given your trusted document keeper..**
- ✓ **Update the Transition Planning form** with any changes in plans, needs or preferences, and with an eye toward the transition assessments that were completed last year. If assessments weren't done, are outdated, or were inadequate, advocate for new ones.
- ✓ **Make a decision about whether your family member will need guardianship, or some other form of formal assistance from you, after age 18.** After 18, none of your care team members will be able to consult with you unless you have established a legal route for that, as your child will be an adult and entitled to privacy and independent decision-making. Less intrusive alternatives to guardianship can include Supportive Decision-making teams as well as health care proxies and/or obtaining a durable power of attorney. See page 18 of [this guide](#) for a checklist of questions that can help guide your family through guardianship discussions, and [here's more information](#) on some of the alternatives.
- ✓ **If your child is male, register for Selective Service before their 18th birthday.** It doesn't mean they are joining the military, but [registering for the draft](#) is required for some federal benefits. It's also required by law.



## AGE 17 THINGS TO THINK ABOUT:

- ☑ **Can your family get paid for your caregiving work in the home?** Through the Adult Family Care (AFC) program, family caregivers of adult children with significant needs, *if they are not also a legal guardian*, may be eligible to receive between \$10,000 and \$18,000 a year tax-free through an agency funded by MassHealth. There's more information about AFC [here](#) from one provider agency, and a full list of the many other Massachusetts AFC provider agencies [here](#). You can apply as early as 16, but the eligibility requirements are easier to satisfy after your child becomes an adult at 18. So start thinking about it now if you haven't already!
  
- ☑ **Is college an option?** There are colleges in New England that accept special needs students both with or without a high school diploma. Most of them provide targeted support services for disabilities including autism, ADHD and mental health needs. Here's [a list of some of the post-secondary options](#), maintained by the Concord SPED PAC.





## AGE 18 TO DO:

*Buckle your seatbelt; this is a big year. Don't panic though, if you've been following along with this guide you'll be positioned well for the year ahead.*

- ✓ **Reread the sections above, and consider whether you might have missed something.**
- ✓ **Update the document file you've given your trusted document keeper.**
- ✓ **Update the Transition Planning form** with any changes in plans, needs or preferences, and with an eye toward the transition assessments that were completed last year. If assessments weren't done, are outdated, or were inadequate, advocate for new ones.
- ✓ **Set aside some dedicated time throughout this year for your work on transition.** How much time depends on your family member's needs and plans, but you will want to identify a few days over the year to do the paperwork required.
- ✓ **Apply for a Section 8 housing voucher from the U.S. Department of Housing and Urban Development.** It is important to apply for this years before you will need it because you may be on the waiting lists for more than 10 years in some instances. Here's a [link](#) with information about how it works, and the [Autism Housing Pathways](#) Turning 18 list will be your best friend as you go through the process, explaining the multiple options available and how to choose between them.
- ✓ **Apply for Social Security Insurance (SSI) or Social Security Disability Insurance (SSDI) benefits.** While both provide support to people with disabilities, SSI is intended for people with no or limited means of support, while SSDI is a benefit that you receive because you or a parent has paid into the Social Security system through working. Here's [a great primer](#) that explains the difference and you can apply [here](#).



## AGE 18 TO DO:

- ✓ **Check on health insurance:** Both SSI and SSDI are likely to entitle your rising adult to receive help with health costs through a government program such as MassHealth (Medicaid) or Medicare. You will probably receive a card in the mail without applying. If your family has health insurance through a job or another source that covers your rising adult, you may be able to get reimbursed for the cost of your premiums. It's called MassHealth Premium Assistance, and here's [a link with more information](#).
- ✓ **Apply for benefits from the Supplemental Nutrition Assistance Program (SNAP),** formerly known as food stamps, if your rising adult is eligible. You can [check eligibility or apply here](#).
- ✓ **Apply now for AFC caregiver reimbursement** if you qualify and haven't already done so. (This can provide between \$10,000 and \$18,000 a year in tax-free benefits; see "Things to Think About" in age 17 section above for more information.)
- ✓ **Apply to college or post-secondary training programs,** if that is your path. *See: Is College and Option? above for a list of programs that support students with special needs, or go [directly](#).*
- ✓ **Talk to your young adult about an "ABLE" account.** ABLE accounts are special investment savings accounts that are exempted from the savings limits otherwise imposed when receiving government benefits such as SSI or Medicaid. In Massachusetts, the plan is managed by Fidelity Investments. There's more information about ABLE accounts in general [here](#), and about the Massachusetts plan [here](#), or you can open an account online through the Fidelity site [here](#). In most states, there are consequences for estate planning, so you should be sure to review the pros and cons before opening an account. And here's a [video](#) from the Massachusetts ARC that nicely explains ABLE accounts.



## AGE 18 THINGS TO THINK ABOUT:

- When is the best time for meetings of your expanded transition team?** This group of trusted family members, friends, helpers, clinicians and other people that your young adult likes and respects should plan to meet several times over the remaining months. Having this group in place can be reassuring to both you and the transitioning young adult as they contribute to planning and provide a network of support for the future. If you agree, add **“Schedule Transition Team Meetings”** to your “Things to Do” section for the relevant years. If getting together in person is difficult, you can schedule these as virtual meetings. Be sure your young adult is included and has the opportunity to be heard!
  
- Begin to think about the type of adult service plan that will work best for your family. (see ages 19/22)**





## AGES 19-22 TO DO:

- ✓ **Reread the sections above, and consider whether you might have missed something.**
- ✓ **Update the document file you've given your trusted document keeper.**
- ✓ **Update the Transition Planning form** with any changes in plans, needs or preferences, and with an eye toward the transition assessments that were completed last year. If assessments weren't done, are outdated, or were inadequate, advocate for new ones.
- ✓ **If you have not already had your Individual Transition Plan meeting**, you should talk to your school district about doing that no later than nine months prior to graduation. Any plan developed by the school can be appealed by the student or parent.
- ✓ **Find an adult primary care physician** and an adult dentist. Ask your pediatric professionals for recommendations to clinicians who might be sensitive to your young adult's specific needs and sensitivities. Also reach out to your friends and other special needs parents; consider using Facebook groups or other social media.
- ✓ **Pick the adult service model that best suits your individual/family needs.**

Massachusetts offers both **traditional** and **self-directed** service models for people who are eligible for support through the Department of Developmental Services. The right to self-direct services is part of a national movement toward empowering people with disabilities to decide the course of their own lives. In Massachusetts, it's guaranteed by the "Real Lives Law of 2014," which gives eligible participants the opportunity to use their allotted budget to purchase supports and services that meet their needs and goals. The difference between the traditional and self-directed models is described in [\*\*this slide show\*\*](#), prepared as a training tool for DDS staff.



## AGES 19-22 TO DO:

Under the **traditional model**, DDS contracts directly with an agency to provide services and supports. This can include shared living arrangements, help with employment, and day programs. This is the most common model in use in Massachusetts.

There are two types of **self-directed models**:

**Agency with Choice (AWC) Model:** The individual and family partner with an agency to hire and maintain staff. The agency handles the payroll and administration aspects of the staff relationship.

**Participant-directed Program (PDP) Model:** This model offers the greatest flexibility, allowing the individual and their family to design a custom program and pay for it with DDS funds. 3LPlace (we're the ones who created this guide) is primarily funded through the Participant-directed Program.

There's more about Agency with Choice and the Participant-directed Model [here](#). Scroll down to "Choosing Which Service Method is Best for You (2016)." Much more information about the underlying concept of self-direction is available through the website of this organization, [Applied Self-Direction](#).

While it may be possible to find a fit for your family member in any of the available models mentioned above, a 2020 evaluation of Massachusetts' DDS services by the Human Services Institute found that:

*"Participants in the Participant Directed Program (PDP) and Agency with Choice (AWC) models overwhelmingly report that their life is better since they started self-directing, that they would recommend self-direction to others, that they have more choices and control in their lives, and that they feel more confident."*



## AGES 19-22 TO DO:

- ✓ **As you begin to consider adult services,** here's [a link to a list of questions that are worth asking](#) of any provider agency. It covers important things like regulation, structure, safety, limit-setting and team dynamics. 3LPlace developed this list based on questions we are frequently asked by individuals/families. As you consider potential placements, ask yourself: Will this place and these people be committed to fulfilling our goals, as an individual? As a family? Do they have the resources and structure built into the program to carry out my young adult's aspirations?
- ✓ **Check again for eligibility for [SNAP \(food stamps\) benefits](#).** Upon turning 22, people living with their parents may become eligible even if they have not been previously.





## AGES 19-22 THINGS TO THINK ABOUT:

- ✓ **If a student is still in school**, apply all transition requirements for age 14 and higher.
- ✓ **If work will be an important option for your adult**, obtaining and keeping a part-time paying or volunteer job during this time will prepare you to determine any vocational supports that might be useful moving forward.
- ✓ **Revisit housing plans** for the future in the context of a whole life plan. As we mentioned above, [\*\*The Autism Housing Pathways website\*\*](#) is an invaluable resource, regardless of whether you/your family member carries an autism diagnosis. At the same time, you will probably want to identify the other building blocks of your family member's meaningful adult life before making decisions about housing.
- ✓ **Your young adult is about to leave the school community that has likely been an important social connection for them.** Having other social networks, relationships, and recreational activities in place will be increasingly important as your family member moves ahead. This is a significant part of any plan for a full and meaningful life. If your young adult is ready for it (they get to make this call, not you), consider a course about relationships, love and sex. There are also options available for online dating for people with autism, or other disabilities.
- ✓ Here are some links to information about recreational opportunities across the state:
  - [\*\*Massachusetts recreation fact sheet from the Shriver Center at UMass Worcester\*\*](#)
  - [\*\*Adaptive recreational programs in Massachusetts state parks\*\*](#)
  - [\*\*Pools, beaches and a calendar of events\*\*](#)
  - [\*\*Special Olympics sports, recreation and fitness\*\*](#)



## AFTER 22

*Launching into adulthood as a special needs family can feel like stepping off a cliff.*

*Preparation will help determine how successfully you fly!*

The preceding pages have offered guidance on the following:

- Post secondary training or study
- Employment and employment training
- Adult services after age 22
- Future housing needs
- Government benefits and supports
- Adult medical and dental care
- Future decision-making, with or without guardianship
- Social and recreational connections

It's time for a pat on the back. That was a lot of work!

This section of Transition Tools and Tips will offer some perspective and suggestions about life after 22: that is, life after the school services provided under IDEA have ended.



## **Support from a different source, with different rules**

As we've discussed earlier, when your young adult reaches 22, they are no longer covered by the federal Individuals with Disabilities Education Act, which means your local school district is no longer involved in their education and support services.

Your school district will have referred you to a state agency, which will conduct a review of your situation and determine eligibility for adult services. If you are found not eligible, there are two levels of appeal.

Advocacy will be critical moving forward. State agencies are understaffed and underfunded and you need to ask and advocate for everything that your young adult will need for a full and happy life.

Try to be as organized as possible. Keep careful records of all communications. Keep a calendar of upcoming meetings with special attention to the opportunities for review, changes and updates, such as the annual meeting to review the Individual Service Plan (if you are working with the Department of Developmental Services).

You will want to pay particular attention to the budget you are allocated and the basis for that. You can ask agency staff how they determined the "assessed need" for your family member, and what tools were used. Then, compare that picture to what you know to be true: Is it accurate? Have things changed since the last assessment?

Your budget will be more transparent to you if you've selected the "participant-directed" model described above. But even if you have chosen traditional programming, you have the right to know how much the agency is spending on your behalf. And, if you have chosen to self-direct your programming, ask what your budget would have been in a traditional setting. The two numbers should be about the same.





**It's probably time to point out that even if you've done everything right, stuff can happen.**

Experiences can vary based on staffing and budgets in adult service agencies. If there are gaps, don't blame yourself, all the tools and information you need to fill them are available and Massachusetts has some phenomenal organizations providing individuals and families with help and support.

**Here are some of them:**

[\*The Federation for Children with Special Needs\*](#)

[\*The ARC of Massachusetts\*](#)

[\*The network of Autism Support Centers\*](#)

[\*AFAM: Advocates for Autism of Massachusetts\*](#)

**Facebook groups for families with special needs, including:**

[\*Massachusetts Transition to Adulthood\*](#)

[\*MAK Resources\*](#)

[\*Parents of Neurodiverse Kids MA\*](#)

[\*Transitioning Our Kids With Autism Into Adults\*](#)

**We'd also like to offer a bit of perspective about what's important** at the start of this new beginning.

In 2011, an inclusive group of UK researchers, including both people with disabilities and without, set out to determine what things were likely to help people with developmental disabilities feel happy and satisfied with life. "We decided we wanted to talk to people who say they are very happy about what things help them feel like this," they said.

Here's what they reported:

"There are lots of things that people with a ... disability think (are) important to be happy and satisfied. People need good things in their environment like **relationships, choice and independence, valuable roles, somewhere to go and someone to go with.** The people we spoke to also told us that it is important to have **staff and family that enable them to lead happy, fulfilling lives and overcome the boundaries that they experience like not having enough money or transport.** Finally, people told us that **the way you view life and the way you manage difficult emotions** are also important."

Best of luck on the road ahead. You've got this! And if you need any help along the way, you can [\*\*contact us\*\*](#) or read more about 3LPlace [\*\*on our website.\*\*](#)





## TO DO SUMMARY:

### AGE 14

- Begin IEP Transition Planning & [Transition Planning Form](#)
- Review this [fact sheet](#)
- Apply for a [non-driver's identification card](#)
- Review the [Life Course Nexus](#)

### AGE 15 to 16

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Confirm your school has submitted a "Chapter 688 referral" if they have not submit on your adults behalf.

### AGE 17

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Decide about guardianship ([use this guide](#)).
- If your adult is male, [register for Selective Service](#) before their 18th birthday



## TO DO SUMMARY:

### AGE 18

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Apply for a Section 8 housing voucher ([use this guide](#))
- Apply for [Social Security Insurance or Social Security Disability Insurance](#)
- Check on Health Insurance options, coverage, entitlements
- [Apply for benefits from the Supplemental Nutrition Assistance Program](#)
- Apply now for [AFC caregiver reimbursement](#)
- Apply to college or post-secondary training programs ([list of programs](#))

### AGE 19 to 22

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Hold Individual Transition Plan meeting no later than 9 months prior to graduation
- Find an adult primary care physician
- Pick the adult service model that best suits your individual/family needs