



# Tools for Tomorrow

Pocket Guide



## Here Is Where to Start

This guide will assist you as you develop supports/services in the community for yourself or your family member. Rather than starting with a blank sheet of paper, use it to make your journey easier. It begins with your Vision of a good life, and guides you through choices that make your Vision possible using the supports/services that you need.

Your vision can be developed informally or through a formal process such as person-centered planning.

In any case it is important to step back, whether you are an individual with a disability or an involved family member, to think about what a “good future” would look or feel like. The time taken to identify a vision is well worth it, whether it takes you 3 hours or 3 days!

As you learn about what is possible through supports/services, you will likely change your ideas about bringing the Vision to life. Keep an open mind about changes. The cycle of learning and changing your ideas is an important step in making your Vision possible. If you would like to read a short story about another person’s vision, go to the end of the pocket guide where two stories have been provided before the Appendix.



## The Journey to Your Vision

- 1.** Begin your journey by pasting or writing your Vision in this guide (see page 5). The Vision describes the lifestyle you seek. If it is two or more paragraphs long, attach it to this guide.
- 2.** Add two important helpers to make your trip a success. The first is your Non-Negotiables that are the important issues that you will not compromise. The second is the people who are your Circle of Support. (these individuals should understand and support your vision) List the Non- Negotiables and your Circle of Support on pages 6 and 7.
- 3.** Next, go to the community to explore, visit, interview and discuss. The community includes much more than service providers and clinical supports. Contact people and groups that you trust, and some that are new to you that seem trustworthy, since you have “checked them out.” Consider searching credible sources on the Internet. Examples of experts and groups to contact are those knowledgeable about employment, housing, transportation and recreational activities.
- 4.** Now, explore, visit, interview and discuss with service providers and other supports: these are the resources that you might have regular, perhaps daily, contact. Exploring includes trips on side roads to consider alternative providers and supports that are different from your initial thinking. You can expect that some side roads will be dead-ends, but one or more might bring you closer to your vision than other choices.

- 5.** Be alert that some supports/services are offered as packages, yet you may want one or more pieces and not others. One example is a residential program that meets your Vision, but you want to participate in a day program from another provider. You may be pressured to consider the whole package on a take-it or leave-it basis. Rather than give up on accessing certain pieces, carefully explain your Vision, and which supports/services are important to you. You may find a solution that works for you or your family member, and for providers.
- 6.** Make a pit stop by contacting your Circle of Support and sharing with them what you now know. They will likely contribute ideas and names of people to contact. They might even have a breakthrough suggestion that results in an even better outcome to your journey.
- 7.** You are almost to the top of the hill. Using paper, explore various ways (or strategies) to make your Vision possible through the supports/services that you need.
- 8.** If you have not done so, it's time to include the funder (Department of Mental Retardation or other state agency). They will have suggestions on supports/ services (including new ones that need checking out), and definite opinions on cost for ones that you are considering. The meeting with the funder may result in a collision, a minor fender-bender, or it could get you on a fast lane to your Vision. Whatever the outcome, you can now include their viewpoint in planning your supports/ services.
- 9.** With your Vision and Non-Negotiables in mind, sort the various ways of achieving your Vision, from most-desirable to least-desirable to unacceptable. Be alert that the funder may have limited resources for supports/services to meet your Vision.
- 10.** You are near the end of your journey, but you may need to check in again with your Circle of Support. See if they arrived at the same or similar way of sorting how you can achieve your Vision. If they did not, try to understand why, and open the discussion to changes. You should seek agreement with most or all of your Circle of Support.
- 11.** You finish the journey by meeting with the funder for an Individual Service Plan (ISP is the abbreviation used in this guide). This is when you agree on the supports/services that you need. At this point, there should be no surprises, but only minor adjustments. Congratulations on an outstanding and rewarding trip!
- 12.** You should keep this Guide with your Vision, Non-Negotiables and list of people in your Circle of Support for future ISPs, which are either reviewed or rewritten annually. You will also find that your Vision, Non-Negotiables and Circle of Support change over time, compared with those listed in your guide. When changes occur, it is worth thinking how they impact your supports/ services.
- 13.** This pocket guide is written from the perspective of the individual with a disability. Family members may need to play an active, sometimes central role, in coordinating this process. But keep in mind that this is about the individual, “nothing about me, without me.”

## Items and Ideas to Take on Your Journey

**Your Vision** Examples are where you want to live, with whom you want to live, what you do during the day, what you do during the weekend, the clinical supports that you want, what you do for fun and recreation, and what kind of lifestyle you like. Write or paste your Vision here, or attach it to this guide:



**Your Non-Negotiables** The parts of your life that are absolutely essential to your future success. Examples are lifestyle (two are privacy and family involvement), staffing and clinical supports, location of home and availability of recreation. Write or paste your Non-Negotiables here, or attach it to this guide:



**Your Circle of Support** List those people whom you trust that understand your Vision in detail, and can help you choose among choices that you are considering. Include between three and eight people who are a mix of family, friends, and people who have some experience with the supports/services that you are considering. You may find that it is hard to ask people for help. Almost always, you will be pleasantly surprised that they are willing to help. Write or paste the names of your Circle of Support here, or attach it to this guide:



**Specific Support Needs** If you don't know, keep a diary for 30 days, both weekdays and weekends. Each type of support or help or activity should be one line. Each line should have a total number of times used over the 30 days. Write or paste the supports or help or activities here, or attach the list to this guide:



**Negotiation Strategies** A negotiation is not an argument; it is an attempt by two or more people to find areas of agreement so they can work together. In a successful negotiation, you only need to agree on important points, not on everything. It is common to negotiate with service providers, clinicians, housing providers, transportation providers, employers and funders. Here are suggestions for success:

- ▶ Keep focused on what you really want, and not be too concerned about less important objectives.
  - ▶ Repeat what people say so everyone understands what is being discussed.
  - ▶ Don't decide at that moment.
  - ▶ Practice with someone in your Circle of Support before important meetings.
  - ▶ Include your Non-Negotiables in discussions.
- When all else fails, use the influence of your Circle of Support and others that you know. They may be able to explain to community leaders and elected officials about your Vision and the resources needed for services/supports.

**Employing Your Own Supports** One option is to employ your own supports, rather than contracting with a provider for supports. A big advantage is that you have direct control of the supports, but you need to think about your responsibilities as an employer:

- ▶ Business side - Completing forms, writing paychecks and paying bills (Sometimes a provider handles the business side under contract.)
  - ▶ Personnel side - Recruitment, supervision, training and termination (Sometimes a provider handles one or more parts of the personnel side.)
  - ▶ Coordination of supports/services to be at the right place at the right time
  - ▶ Quality side - Insure health and safety, provide for in-service training, assure satisfaction, assure comfort
- Implementation so that it meets your lifestyle needs

**Items to Consider in a Support/Services Plan** It is easy to overlook important details. Use this as a starter checklist, and modify for your supports/services:

- ▶ Staff - hours and pay rate, tasks that are specific to your activities like morning preparation, clothing, menu planning, and evening preparation
- ▶ Housing - shared or private, rent or purchase, utilities, maintenance, food
- ▶ Transportation - availability, accessibility, access to public transportation
- ▶ Clinical supports - availability, ability to coordinate specialties, travel distance, insurance
- ▶ Recreation - personal interest, availability, choices, schedule

**Financial Resources** Common financial resources include the following:

- ▶ Individual/Family
- ▶ State funding agency
- ▶ Personal Care Attendant funds
- ▶ Housing voucher
- ▶ Social Security and SSI
- ▶ MassHealth Insurance
- ▶ Medicare (if 65 or more years old)

**Living with family vs. living alone or with others** Here are items to consider:

- ▶ Living with family brings you and your family together in a very direct way. To be a success, you and your family need to maintain your senses of identity and good humor to help everyone through inevitable conflicts. If you receive Social Security (SSI) payments, that money is yours, and often becomes part of the total family income.
- Living alone or with others is more independent, but you need to think about all aspects of the supports/services plan as listed above. If you live separately from your family and receive SSI, that money is yours to spend on rent/ food and other expenses.

**Broker for Supports/Services Brokers** can represent you in your search and negotiation for supports/services. They have advantages and disadvantages as follows:

► **Advantages** - Brokers bring their expertise. If their expertise complements your knowledge about services and supports, then working as a team with a broker makes sense. Their expertise can be helpful during negotiation with service providers, funders and others, not only on dollars, but on the important details of supports/services.

**Disadvantages** - You must work hard to bring a broker into your Circle of Support. A broker is only effective if they understand your Vision and help you choose among supports/services to achieve it. Brokers charge you a fee, and you must decide if their service is valuable, and how you will pay for it.

**Turning 22** Here are the important points to consider about the Turning 22 law (Chapter 688):

► Special education (ages 3 to 21 inclusive) is funded through the local educational system. Educational services are an entitlement, meaning that if you qualify, you must be provided with those services. In special education, each student must have an Individual Education Plan (IEP). In Massachusetts, special education services and funding end the day before your 22nd birthday, without exception.

Adult services start on your 22nd birthday and are funded through a state agency (such as the Department of Mental Retardation). You now have an Individual Service Plan (ISP), rather than an IEP. Funding is through the state budget, not the local educational budget. Some providers are the same for educational and adult services, but most are not. Adult services are definitely not an entitlement, which means that services are not guaranteed.

**Agency Checklist** Here are points to consider when evaluating a prospective agency for supports/services:

► What is the provider's mission? Does it encompass the services and the intent that you are seeking?

How can I obtain a copy of the most recent licensing survey?

Ask the agency to describe the screening process used to hire staff.

What training does the agency offer staff?

How are the direct service staff supervised?

What are the names of people and/or families who currently receive services that I can talk with about the agency?

Does the agency have a consumer/family organization? What role does it play?

What backup systems are in place for medical or behavioral emergencies?

How does the agency actively assist people to make choices?

How much say-so does the person receiving services have in deciding where he/she lives and with whom she/he lives?

Are agency staff capable of effectively implementing the support plan (including values, cultural and personal aspects)?

How much say-so do people receiving services have in deciding and selecting the staff who work with them?

What recreational and social activities do people participate in? How individualized, available, accessible, and consistent are they? How often do people participate in these activities? What happens when individuals choose not to participate? How does the agency help people learn to be part of the community?

*Adapted from Service Coordination, The Arc of Frederick Count, Inc.; Signs of Quality by People on the Go of Maryland; and The Arc of Maryland.*

## ▶▶ Jack

Jack had turned 22 years of age. His family had thought that this would be the beginning of a period of transition for him to community living. Part of Jack's dream (and that of his parents) was moving to a setting independent of them, where he could develop as an adult.

Jack was able to obtain work and transportation services through funding from the Department of Mental Retardation (DMR). He was in a positive, productive environment. That was good. However he and his parents felt that they had hit a brick wall when they tried to address independent living or residential supports.

Fortunately they had always felt that education was a continual process for themselves as well as Jack. So they didn't give up. They initiated a Circle of Support which included friends, family, advocates, and some paid supporters. It was a source of encouragement and support.

Jack and his family, supported by a Circle of Support, learned all about the different options available for housing and support services. They took advantage of the expertise in their circle and did the following:

1. They identified goals in Jack's ITP (Individualized Transitional Plan) to move into a home of his own which included features that were important to him.
2. They made sure the goal of community living was reflected in some way within the Individual Service Plan (this is developed by DMR after an individual has finished his/her transition period from school).
3. Jack and his parents applied through MassHealth for Personal Care Attendant Services so that Jack could begin his transition outside the home with these support services.
4. They filled out applications for different housing vouchers (e.g., AHVP through local housing authorities) which would partially subsidize his rent in his new home.

Only eighteen months after facing a brick wall, Jack and his family were successful in obtaining Personal Care Attendant Services and a housing voucher. Jack began a transition process on a part time basis with support from his family and some circle members. Eventually, he spent several days each week at his new home while returning to the family for a few nights of the week.

One of Jack's support staff has bonded especially well with him, enjoying similar activities. The family realizes that this is a work in progress and together they will work to keep this dream moving forward.

## ▶▶ Daniel

Like his high school classmates, Daniel spent an increasing amount of his school day preparing for life after high school. Some of his classmates (without disabilities) worked on internships or in apprenticeships in local businesses. Daniel worked with a job coach in community businesses. After his senior year, academic programs focused on life and community participation skills (Daniel was still entitled to education services, until his 22nd birthday). At his job site, he sorted and delivered mail (which was coded as he did not read), shredded documents and handled other office tasks.

Staff changed at Daniel's school and program. Daniel was assigned to the local sheltered workshop for a traditional evaluation. After weeks at the workshop it was determined that:

1. Daniel was in no position to work outside the workshop now or any time soon.
2. Daniel required day habilitation services.
3. Daniel required behavior support.

Luckily Daniel and his family did not accept this assessment. They did try to explain what his recent work experience had been like. They were told that another meeting would be scheduled to review his case. The family brought in an advocate to assist them with the school. At the second meeting it became apparent that Daniel was given tasks through the "traditional evaluation" that he was physiologically unable to perform due to his Cerebral Palsy. Since he was unable to complete the tasks he became frustrated and started acting out. In addition, this usually social young man was not allowed to speak except during breaks. Daniel then got in trouble for talking and fooling around.

The advocacy paid off. Daniel now works at local businesses through a small company. With a job coach initially paid for by the school district, Daniel went to his clients where he shredded documents. The job includes regularly scheduled appointments which has enabled Daniel to develop relationships with people at each office. Besides participating in a meaningful task, Daniel like many workers has the opportunity to socialize.

After "Turning 22," Daniel's job coach was paid for by DMR. By starting the process early during his teen years and advocating through a rocky period, Daniel and his family were able to implement his vision.

## Information Sources

Tools for Tomorrow, a 24-page booklet, describes some of the steps above in more detail, and is a source for the content of this pocket guide. It is available from The Arc of Massachusetts ([www.arcmass.org](http://www.arcmass.org) or 781 891-6270)

Massachusetts Families Organizing for Change ([www.communitygateway.org/info/c](http://www.communitygateway.org/info/c)),

Massachusetts Advocates Standing Strong ([www.massadvocatesstanding-strong.org](http://www.massadvocatesstanding-strong.org) or 781 585-2422) and Massachusetts Developmental Disabilities Council ([www.state.ma.us/mddc/](http://www.state.ma.us/mddc/) or 617 770-7676)

Allen, Shea & Associates is a professional service organization with a list of resources for families planning, choosing and evaluating services and supports at [www.allenshea.com/familyresource.html](http://www.allenshea.com/familyresource.html)

Family Village lists resources for people with disabilities. [www.familyvillage.wisc.edu/index.html](http://www.familyvillage.wisc.edu/index.html)

Inclusion Press offers various materials on inclusion, in a school setting and for adults living in the community. [www.inclusion.com](http://www.inclusion.com)

Institute for Community Inclusion at University of Massachusetts, Boston and Children's Hospital, Boston. ICI develops resources and supports for people with disabilities and their families to foster interdependence, productivity, and inclusion.

Information on their publications is at [www.communityinclusion.org](http://www.communityinclusion.org)

Institute on Community Integration at University of Minnesota has some good products related to housing and transition. <http://ici.umn.edu/products/default.html>.

John O'Brien and Connie Lyle O'Brien produce materials on person-centered planning, community building, and innovative services. <http://soeweb.syr.edu/thechp/rsapub.htm>

The ArcLink provides information on the human service system for many states, including Massachusetts. It has information on providers. [www.hearlink.org](http://www.hearlink.org)

For Massachusetts, the Massachusetts Department of Mental Retardation ([www.dmr.state.ma.us](http://www.dmr.state.ma.us) or 617 727-5608)

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*Tools for Tomorrow is a partnership between individuals and families:*

The Arc of Massachusetts,  
Massachusetts Families Organizing for Change,  
Massachusetts Advocates Standing Strong and the  
Massachusetts Developmental Disabilities Council

Tools for Tomorrow asks that individuals, family members and guardians answer specific questions about how a person wants to live their life. Therefore, they determine the “best way” for themselves, taking the decision making out of the hands of people who are not family, guardians, or the individuals themselves. Isn't this what life is all about: the respect and dignity of being informed, assessing your situation and being able to make your life the best it can be? Tools for Tomorrow is one more step to help make this happen.

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