

SECOND EDITION

THE Special Needs Planning Guide

*How to Prepare for
Every Stage of Your Child's Life*



CYNTHIA R. HADDAD
JOHN W. NADWORNÝ

The Special Needs Planning Guide

How to Prepare for Every Stage of Your Child's Life

Second Edition

by

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and

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About the Authors

Since the early 1990s, Cynthia and John have worked together as pioneers in the field of special needs financial planning. When they first started their careers, there were no guidelines, references, or research available to help them advise families in planning for their and their child's future. They pulled from their own personal experiences as a sibling and a parent and their professional knowledge to create one of the first comprehensive resources for professionals and families in writing *The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life* (Brookes Publishing, 2007).

As thought leaders and subject matter experts on the topic of planning for people with disabilities, Cynthia and John are quoted extensively in the media. They continue to share their passion and understanding as noted authors and speakers in providing financial planning information on related topics to families, organizations, and professionals. They have presented hundreds of pro bono informational workshops and participated in panels of professionals and families throughout the United States. They have held positions of leadership and served on various boards of organizations throughout their careers as fervent advocates for individuals with disabilities.

In 2019, after working together for nearly three decades, Cynthia and John founded their own firm, Affinia Financial Group, a Registered Investment Advisor, in Burlington, MA. Affinia Financial Group conducts business under the Special Needs Financial Planning name. Advisory services are offered through Affinia Financial Group, LLC, a registered investment advisor. It is Cynthia and John's intention to pass their knowledge and experience on to future generations of advisors and families.

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Cynthia grew up watching her parents love and care for her older brother with special needs, while juggling the needs of the whole family. She understands firsthand that lives are complex, and with each day comes the possibility of new challenges

and successes. Early in her career, she began to view her profession through a personal lens, recognizing the unique nature of the financial planning requirements of families like her own. Cynthia applies her extensive planning skills and empathetic approach to her practice in advising individuals, families, and trustees. She understands the importance of taking a pragmatic approach to the planning process and focuses on communication, guidance, and encouragement to keep her clients' actions aligned with their goals.

Cynthia earned a Bachelor of Arts in finance and economics from Simmons University (formerly Simmons College) in Boston. She is a member of the Financial Planning Association and the Academy of Special Needs Planners.

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John had both his career and family well under way when his third child, James, was born with special needs. This life event immediately and dramatically changed both the course of his plans for the future and his priorities. Planning with families over a span of decades has provided John with an education like no other. This specialized knowledge allows him to understand the personal and financial resources needed to present viable options and possible solutions for families with unique and challenging circumstances.

John received industrywide recognition when *Investment News* chose to feature him and his family as the cover story of their September 2017 issue, which was devoted to planning for individuals with special needs. It also produced a video, *A Father First*, telling the story of John's interwoven personal and professional lives. In Massachusetts, John was also a proud participant in the rollout of the Achieving a Better Life Experience (ABLE) account.

John has earned a Master of Business Administration from Babson College, a Master of Science from Bentley College, and a Bachelor of Science from Bridgewater State College. He is a member of the Financial Planning Association and the Academy of Special Needs Planners.

Financial planning and investment advice are offered through Affinia Financial Group, a registered investment advisor.

About the Contributor

Leo V. Sarkissian, MASW, LICSW, Executive Director

The Arc of Massachusetts, Waltham, MA

<https://thearcofmass.org/>

Leo has led The Arc of Massachusetts as Executive Director since 1991, after entering the disability field in 1976. During Leo's tenure, The Arc, a statewide advocacy organization:

1. Insured adult transition services for graduating students (now 1,300 annually).
2. Expanded Family Support or Respite programs to \$84.9 million.
3. Changed eligibility regulations so that persons with intellectual or cognitive disabilities could participate in the Personal Care attendant program.
4. Worked toward passage of several bills, including self-direction, service to adults with autism spectrum disorder (ASD) and developmental disabilities, and a registry for staff substantiated for abuse.
5. Established community services for 3,844 individuals through settlements from two waiting-list cases.
6. Established a strong education-outreach record with publications and website tools to assist individuals in planning housing, person-centered planning, and social inclusion. A health equity program reaches five medical or graduate nursing programs.
7. Saw the Massachusetts Department of Developmental Services grow to become a \$2.3 billion state agency.

Prior to his statewide advocacy role, Leo oversaw a multi-service agency that provided residential, employment/day, personal care assistance, early intervention, and family support services. He also has served as a clinician with various roles, including counseling, emergency services, and a team member in the development of adult community services.

Leo received his Master of Arts in Social Work from the University of Chicago's School of Social Service Administration in 1979, and he is a licensed independent social worker. He has served on national committees and received several awards during his tenure. He is married and he has two daughters and three grandchildren.

I

Your Planning Essentials



1

The Special Needs Planning Timeline

This book will serve as a guide to help your family plan for the future. Reading through it may relieve your anxieties about planning, or it may raise your awareness about the need to plan. Because every family's specific situation is unique, it is not possible to find one single solution, one financial product, one legal document, or one residential option that fits the needs of every family. There are, however, some basic guidelines and rules that can be applied to form a basis for planning. This chapter will introduce these basic guidelines, along with the general planning timeline for actions a family can take at each stage in the life of a child with special needs.

FAMILY LEARNING GOALS

After reading this chapter, you will begin to understand . . .

- How financial planning for your family is similar to and different from financial planning for families whose children have no special needs related to disabilities.
 - What additional factors families must consider when planning for the needs of children with disabilities.
 - What challenges—or planning pressure points—may come up at different stages in your child's life, and how families can begin preparing for them.
-

COMPARING TRADITIONAL FINANCIAL PLANNING WITH SPECIAL NEEDS PLANNING

When we, the authors, Cindy and John, first began speaking to groups of families, we learned that we had to clarify the distinction between planning for the needs of families who had a member with special needs and planning for the needs of the typical family. The basic needs of both overlap at various stages. For example, the baseline needs of purchasing a home, saving for college and retirement, and estate distribution are similar in both special needs planning and traditional planning. Besides these similarities, families with special needs face additional challenges. Clearly, it is not recommended for families with special needs to adhere to the motto “I’m spending my kids’ inheritance.” Having a child with special needs requires that families plan for two generations and for two retirements. This is because the child with a disability or disabilities may need their parents’ financial assistance and support into and throughout adulthood. This is a common thread throughout this book.

A number of resources such as books, magazines, and newsletters are available online and in other non-print and print media to raise awareness and education for the financial and legal planning needs of families that are considered traditional—that is, families with typically developing children. These families can find an answer to a basic planning question by doing a quick search on the internet on almost any financial topic, or by listening to podcasts, calling in to a talk radio show, or attending public seminars and educational workshops. Information for families with special needs is not as easily accessible—nor are the answers families seek as generally applicable.

To illustrate the differences between traditional planning and special needs planning, we have developed the Special Needs Planning Timeline. The general planning timeline shown in Figure 1.1 outlines the various planning stages or **planning pressure points** that families with children with disabilities need to consider. It demonstrates the differences between the traditional planning timeline and the planning timeline for families of children with disabilities. Keep in mind that these families will want to consider all the aspects of the traditional family planning timeline; however, in addition, they will need to incorporate all the points on the Special Needs Planning Timeline. These planning pressure points are stages that align with natural life transitions in families with children with disabilities. For a child with special needs, the planning pressure points indicate a change in services, supports, and/or benefits that are available. In addition, these are often the points in time when parents feel the pressure to begin planning. We identify each of these points as an indicator that action is needed. The points also highlight the unique planning differences in special needs planning. Each planning pressure point indicates some very specific planning considerations, which will be discussed in detail in later chapters.

We recommend that families build their own personal Special Needs Planning Timeline as they begin the planning process. To help you do so, a full-size timeline template that you can download as an Excel spreadsheet is available on the Brookes Download Hub. You can use this basic timeline as a starting point and adapt it based on your family’s unique characteristics and needs.

THE KEY STAGES OF SPECIAL NEEDS PLANNING

We have developed a simplified approach to help families understand the complexities of special needs planning based on our timeline of planning pressure points determined by the age of the child. Families have very little time to spare

The Special Needs Planning Timeline

5

The Special Needs Planning Timeline: Planning for Two Generations

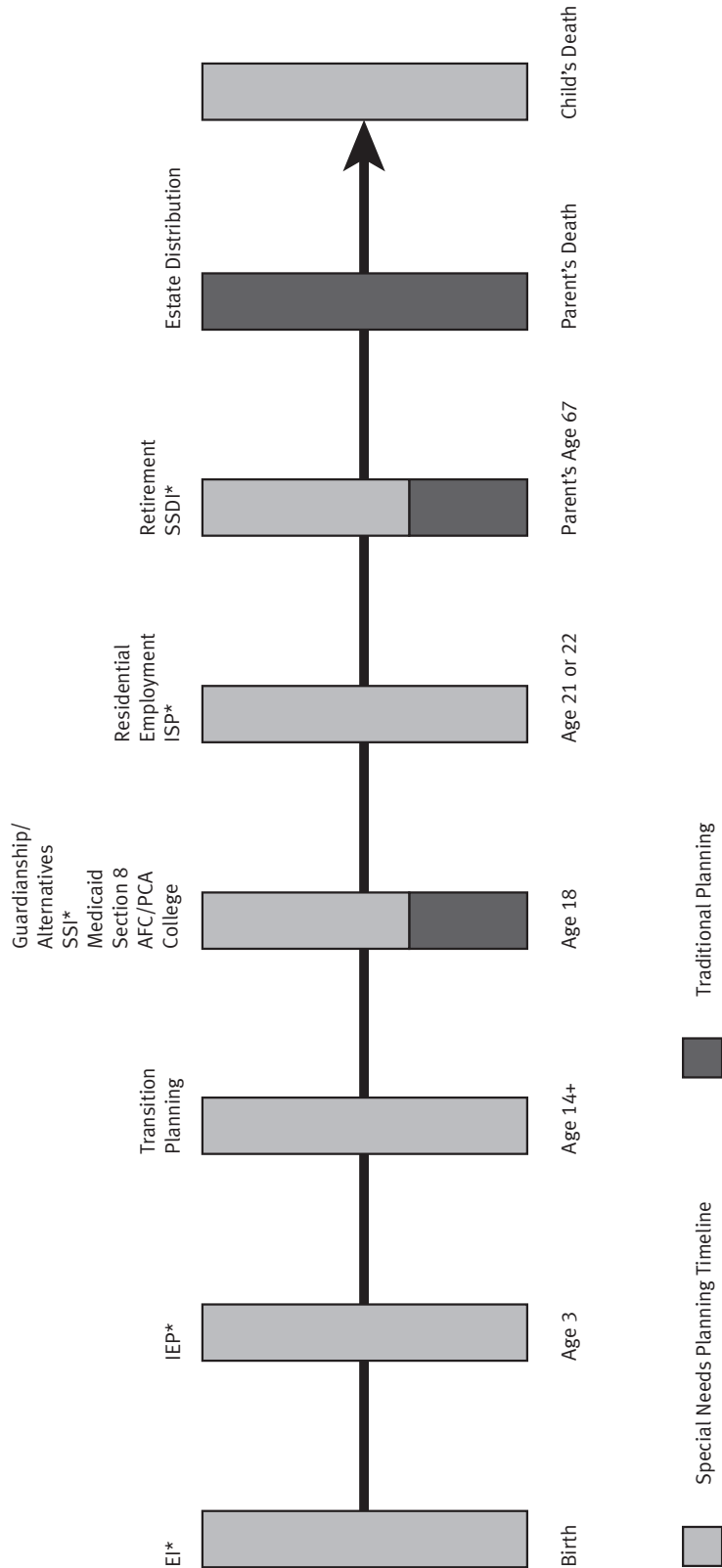


Figure 1.1. The general Special Needs Planning Timeline, showing milestones and planning pressure points which note changes in services, supports, and/or benefits. *Note: Your child must meet certain requirements for eligibility. Benefits and services are not guaranteed. Key: AFC, adult family care; EI, early intervention services; IEP, individualized education program; ISP, individual service or support plan from adult service agency; PCA, personal care assistance; SSI, Supplemental Security Income; SSDI, Social Security Disability Income.

already, but they do indeed need the facts and figures to help them map a course of action to pursue financial security for themselves and their family. The sections that follow discuss the specific concerns, challenges, and needs associated with each stage:

Stage I: Early Childhood (Birth to Age 3). When your child may receive early intervention (EI) services.

Stage II: Transitioning Into the School System (Age 3–14). When your child will be in the school system and may be eligible for special education services.

Stage III: Transitioning Into High School and Government Benefits (Age 15–21). When your child will transition into high school, complete their secondary education, and begin eligibility for certain government benefits.

Stage IV: Transitioning Into Adult Services (Age 22 and beyond). When your child will leave the school system and transition into adulthood, which may include further education, employment, and/or moving out of the family home.

Stage V: Transitioning to the Next Generation—Your Team to Carry On. When you are no longer able to care for your child and making sure you have the people and the supports in place.

Planning Story: James' Family

The types of challenges families face and the supports that are available vary across different stages, as Susan, James' mother, describes:

Going from early intervention services to the public school system was like going from a cruise ship to a dinghy. But going from the public school system to the adult service system was like going from a dinghy to a buoy. We just had to hang on and navigate our way forward.

Stage I: Early Childhood (Birth to Age 3)

If your child's disability is diagnosed between birth and age 3, the primary focus at that point is understanding the diagnosis and obtaining EI services from professionals in the areas of physical therapy, occupational therapy, speech therapy, and medicine. EI services focus on the child as an integral member of the family. EI programs are mostly home-based and community-based. Services can include diagnostic testing through screenings in hospitals or schools and referral services to diagnostic or direct intervention programs.

EI and other services are provided in accordance with an individualized family service plan (IFSP), developed in consultation between families of infants and toddlers with disabilities and the EI support team. The team can consist of occupational therapists, physical therapists, speech therapists, social workers, and other medical professionals. The IFSP is provided for by the Individuals with Disabilities Education Act (IDEA) of 2004. Providing EI early on builds opportunities to help strengthen families. A typically developing child would not require such services.

Please keep in mind that not every disability is identified at birth. Many symptoms can be difficult to recognize at first, and a diagnosis may come later. Getting a later diagnosis or having a disability emerge at a later age may require a family to make adjustments in this portion of the timeline.

Enacted in 1975 as Public Law No. 94-142, the Education for All Handicapped Children Act was amended as the IDEA in 2004 (Public Law No. 108-446), and more recently amended in the Every Student Succeeds Act (ESSA) of 2015. The Act consists of the federal laws for special education services. These laws require state and local education officials to provide appropriate special education services for eligible students. IDEA Part C provides that infants and toddlers with disabilities age birth to 2 years and their families receive EI services. For more detailed information, see the U.S. Department of Education website (<https://www.ed.gov/>).

Additionally, families sometimes face challenges obtaining the services they know their child needs. Some families may benefit from working with a parent advocate, as illustrated by Jake's story.

Planning Pointer for Stage I: Seek Services Promptly

When you discover that your child has a disability, it is important to obtain EI services as soon as possible. In addition, look for parent-to-parent programs in which you can connect with another parent who is raising a child with a disability. Other parents can mentor you and share their information and knowledge. Apply for EI services, even if you think you are not quite ready to start them, because there may be a waiting period. Research shows that the earlier infants receive stimulation and further professional supports such as physical, occupational, and speech therapy, the better these children do in reaching milestones.

Planning Story: Jake's Family

When Jake was 3½ years old, he attended a preschool program. We were still unclear about his disability, but he had limited interest in verbal communication, and he made little eye contact with his peers and with us. The school program was providing him with only one communication activity per week through a speech therapy session. We talked to the special education coordinator, but she stated that only the director of special education can make a change, and that we had to have the change written into Jake's education plan.

After 6 months of going back and forth with no results, we decided to contact the social worker at the EI program that Jake had attended for 1 year. She agreed to meet with us and brought in an educator for part of the meeting. The two of them helped us identify missing elements in Jake's present school program. The social worker also connected us with a parent who was involved in educational advocacy in the same school system as Jake.

After meeting with the parent advocate, we decided to hire her to assist us at the team meeting, which would be to review Jake's current educational plan. At that meeting, the director offered us a compromise for Jake's communication goal, which we accepted pending a 3-month review. We also stated that if progress was unsatisfactory by that time, we would then ask for a mediation session with the school district on Jake's plan and push for the activities that we felt would be optimal for him. We were successful.

If it were not for the assistance of this parent advocate, we would not have accomplished so much on Jake's behalf. There are so many factors that have to be considered, and we are still new to this. Her involvement made such a difference for all of us.

—Jake's father

Stage II: Transitioning Into the School System (Age 3–14)

When your child reaches age 3, your family's first experience with transition will occur. You will be introduced to the educational system, and your child will need to be determined eligible to receive services through an individualized education

program (IEP). The IEP is also provided for by IDEA 2004. The process of creating the IEP will begin with an assessment of your child's abilities and needs. Occasionally, a school district will accept an EI resource plan and suggestions. In most cases, however, the public school system prefers to do its own assessments. It will then provide recommendations for school-based services. Integrated public preschools and some privately funded preschools will support your child's IEP by allowing time for specialists to be a part of your child's school day. The parents' role is critical in working to coordinate with educators and service providers to set measurable goals and objectives for their child. IEP teams can include a number of professionals, and they are required by law to do so. These team members may include occupational and physical therapists, a speech-language pathologist, a school psychologist, a reading specialist, or others. Thus begins your journey of educational advocacy and understanding your roles and rights in the process, as well as the various programs, services, and supports schools may offer your child.

Routines that many families take for granted, such as going to and from school each day, may present difficulties for children with disabilities and their families. Anticipating and acknowledging these, and then exploring options for assistance, can help minimize these difficulties, as Janet's story shows.

Planning Pointer for Stage II: Anticipate New Challenges

Transition to school is a very important period. After a child reaches age 3, the school system is responsible for offering educational and related services. In addition, if a child has special health care needs, such as a chronic illness, a disabling condition, or a frequent need for medical technology, check out eligibility for your state's program that is based on the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) or its Special Health Care Needs Program, informally referred to as the "Katie Beckett" Waiver, part of TEFRA; see Chapter 8 for more information. EI staff will be of great assistance to explore such options, as well to help with the transition to school.

You may face some challenges during the school years, such as:

- Helping your child develop a social network.
- Obtaining an appropriate education program, while helping your child to be included in the everyday life of the school.
- Helping your child learn about their body changes during adolescence.
- Working with your child, beginning at age 15 or earlier, to develop transition goals at school and outside school to prepare for adult life.
- Eventually developing a plan with your child and others who care about what reflects your child's dreams and desires.

Planning Story: Janet's Family

My daughter Janet is 18 years old. She has a wheelchair, which allows her to get around, and although she can understand me, she has trouble expressing herself verbally. My husband and I were finding it difficult to physically transfer her on a day-to-day basis, especially when he travels for his work, because we need a second person to assist. We had to admit sooner than we had hoped that we needed help.

When I talked to a staff person at our local chapter of The Arc, she told me about the **Medicaid** personal care attendant (PCA) program. I learned that the family (or the individual) hires the staff person, and that they can directly negotiate hours. In this case, because Janet is not able to supervise the attendant, I as her parent would serve as a

surrogate supervisor of the PCA. Another benefit is that the PCA, although hired to assist Janet, is also able to help her learn some independent skills beyond the classroom.

I also learned about another program that Janet might be eligible to access, the adult foster or family care (AFC) program, which is also funded by Medicaid. This would allow me or my husband to be paid to be her primary caregiver. The biggest concern with this benefit is that we are both already having difficulty with being able to move her from her wheelchair. We decided that the PCA program would allow us to hire additional helpers. Our life is so much easier now.

—Janet’s mother

Stage III: Transitioning Into High School and Government Benefits (Age 15–21)

By the time your child reaches age 15, if you have not already done so, you should begin planning for the transition to high school. At this point, it is important to maximize the entitlements of education to provide opportunities for vocational exploration, daily living skills, and independence. It is important to locate and establish contact with the government agency in your state that will provide adult services to your child when they are no longer receiving educational services—which will most likely be at age 21 or 22, depending on your state of residence. The agency that is most appropriate to support your child’s diagnosis might be your state’s vocational rehabilitation (VR) agency or the state agency or agencies that serve individuals with developmental, intellectual, physical, or mental health needs.

At age 17½, guardianship and/or alternatives to guardianship need to be addressed. It is also important to begin the exploration of residential and vocational options in your area by identifying the various service provider agencies. Attend workshops and family support groups on such topics as future planning, transition planning, and financial or estate planning. Learn as much information as possible about the variety of adult services and supports in your state and how to access them.

Most local family support agency groups will offer educational workshops and training for families on transition planning. Inquire with your local chapter of The Arc, Autism Support Center, National Alliance on Mental Illness (NAMI), Down Syndrome Society, National Down Syndrome Congress, Center for Parent Information and Resources in your state, a school special education parent advisory council, or other support agencies. Get on their mailing lists or visit their websites and sign up for their blogs. Speak with other parents and share ideas—we all share the common thread of wanting what is best for our children.

When your child is between the ages of 18 and 21 or 22, you will need to plan to ensure that your child has a smooth transition into adult services. There are still many opportunities for higher education to consider at age 18. Typically developing young adults graduate from high school and move to higher education or employment. Young adults with disabilities may also be faced with decisions concerning additional education (college, vocational training, or adult education); however, in addition to these considerations, parents will also want to focus on their child’s independence. In fact, for some families, independence is the primary focus. At this stage, understanding your child’s rights and ensuring that the focus of their IEP is in proper order is paramount to their success in any postsecondary opportunities. It is also important to be aware of various legal and financial issues

that will affect your child's financial security and eligibility for government benefits and services.

At age 18, your child is no longer a minor in the eyes of the law. Although in some situations, parents may continue to make all financial, medical, and legal decisions on behalf of their child with disabilities, the child has the legal right to make their own decisions. Physicians, educators, and service providers have no legally binding obligation to act on your instructions on behalf of your child. This is where the issues of guardianship, or less restrictive alternatives to guardianship, need to be considered. For some, guardianship will be the most appropriate choice, but for young adults with special needs who can make their own decisions, it is less of a default than it likely used to be. The focus today is on supporting the person with disabilities, to enable them to make decisions on their own. This concept is known as self-determination and **supported decision making**, and it allows the individual to have control of their own life. Full legal guardianship of the person may not be necessary, while options of **conservator** or less restrictive options of **power of attorney (POA)** and **health care proxy** may be more appropriate options. These options are discussed in more detail in Chapter 7.

Also at age 18, your child may be eligible for certain government benefits such as **Supplemental Security Income (SSI)** based on their own asset level. Although this is an entitlement program, your child needs to be eligible to receive these benefits. Basically, to qualify for SSI benefits, the individual with disabilities cannot own assets in excess of \$2,000. They can, however, own a home, a nominal life insurance policy, a vehicle, and a prepaid burial account as assets that would not count against their eligibility. Chapter 8 will provide greater detail. In addition, you can visit the Social Security Administration (SSA) website (<https://www.ssa.gov/>) for further information.

Planning for when your child ages out of the public school system may come with added stressors and unknowns about benefits and services. There is no perfect solution for every child right when they turn age 21 or 22. Planning for what they will do all day, how they will get there, where they will live, how they will socialize with others, and who will care for them takes time and creativity. Being flexible enough to know that what you plan for today may not be what they will do for the rest of their life is helpful in your planning and advocacy efforts. Most people do not stay in the same job they have when they finish school, nor do they live in the same home or neighborhood. You will need to explore options, keeping in mind that the availability of residential services may be limited by long waitlists or other constraints. Being open-minded was helpful for Jonas's parents when they were planning his transition from high school to adult services.

Planning Pointer for Stage III: Begin Planning for Adult Services During the Teen Years

If your child is likely to need adult services and supports for any aspect of their life, by the time they are age 18 and still a student, you should start learning about the funding and programs offered. Waiting until the last minute may mean limiting or delaying options in adulthood. Different organizations have materials and books you can read to help you prepare for the transition to adult services. These organizations include The Arc and NAMI chapters. The foundation of your future plan should be developed during the teen years.

Planning Story: Jonas's Family

We felt so much pressure to find housing for Jonas by the time he turned age 22 that we did not stop to think that he had housing—it was in our home. He loved living with us, and we all loved having him as part of the family. There was really no rush to settle for something less desirable than we had imagined with so few options available. We wanted to take the time to find a good home and roommates for Jonas. When we accepted that 22 was not doomsday for housing, we were able to breathe a sigh of relief. We could then focus on where he would work and how to access the transportation to get him to and from work so we could continue with our own jobs. We started with a day program nearby that his school counselors introduced us to. We then secured public transportation from our paratransit service for pickup and drop-off each day. From there, we worked with job coaches to try different jobs until they finally found a great job for him in food services at the local hospital. He loves his job, and with the support of his job coaches, they help him to succeed.

We will continue to look for housing options for Jonas, but now we think we can use the time to plan better and are looking toward his age 30 for him to move out of our family home, which seems a much more realistic timeframe for our family.

—Jonas's parents

Stage IV: Transitioning Into Adult Services (Age 22 and Beyond)

Turning age 22 (or in some states, 21) is another major milestone, and the entitlements of public education stop. Therefore, the individual with disabilities is no longer entitled to receive services from the special education system. There are no federal or state laws guaranteeing entitlement to services after the age of 22. Access to residential, vocational, and transportation services becomes a major challenge for many families. If you do not already, this is a critical time to better understand the state agency from which your child may receive services. Obtain as much information as possible about housing options and the availability of services, and keep in mind that options do exist out there!

This is where the culmination of your efforts in your advocacy and your own personal planning, which you ideally initiated earlier, will come together. Being creative with personal and public financial resources, as well as having a clear vision for your child, can make a tremendous difference in their life.

A parent has many different roles and responsibilities in their child's life. The best-laid plans can fall apart if no one is there to carry on the plans or vision you have for your child. Who will take your place when you are no longer able to do all that you do now? No one person can replace a parent, so it helps to begin the process of building a team of people and resources at every stage of the planning timeline. Having more than one person will help replace the many roles and hats that a parent wears for their child. Joe and Sarah knew that they could not depend on their daughter, who lived in another state, to take over the daily caregiving needs of their son Pat when they died. They also knew that it would take a team of people to replace all that they did for Pat every single day. Their story illustrates the importance of building and implementing their Team to Carry On while they were still healthy and could stay engaged but enjoy time to themselves.

Planning Pointer for Stage IV: Research Government Benefits and Supports

It is never too early to begin thinking about identifying and accessing government benefits and supports. Here are a few suggested steps to help secure government resources for your child:

1. Locate possible programs or funding. Depending on the age of your child, your IEP coordinator, doctor, school system, and other parents are good resources.
2. Determine the most suitable agency that meets your needs. Identify the agency that has a mission related to the disability of your child. In addition, it is important for you to find out which state agencies have the greatest funding. In some cases, your child may have a dual diagnosis and may qualify for services through more than one state agency. If this is the case, refer to your state's budget to determine which agency has the largest resources allocated. You may want to request assistance from an aide in your state legislator's office to help guide you in the right direction.
3. Begin the application process. As soon as you identify an agency that is relevant and which has services you require, ask for an application. If you are uncertain how to complete the application, request assistance from the agency.
4. Get organized from the beginning. Track submission dates and due dates, and then follow up on these dates.
5. Proactively address any barriers to ensure timely completion of your application. If you see gaps in your information, address them through setting up appointments for evaluations or by requesting information that is missing from your files.
6. Monitor the application process. Follow up with the agency once or twice to see whether there is anything you can do to facilitate the application process. Contact them if a deadline has passed.
7. Watch timelines because prompt sharing of records is important to keep in mind. When you are attempting to get an application approved, the date of your application triggers all the deadlines for various steps in the process. If you delay applying, the school, local Social Security office, or state agency is no longer under the same time obligations that are triggered by your application date.
8. Follow up if a case manager misses their deadlines. But make sure you get your necessary paperwork together, so you do not miss deadlines, as well. You can rely on a certain level of responsiveness because most programs have guidelines and regulations that must be followed.
9. Be prepared to advocate for specific supports or services that fit the personal vision of your family member and/or family.

Planning Story: Pat's Family

When Joe and Sarah were young, healthy, and active, they were able to provide 24-hour care for their son Pat at home. They had a great team of supportive caregivers to help them at home, and who became much like part of their family. As Joe retired and the couple got older, they found it more physically demanding and difficult to care for Pat in their home and on their own. Although their daughter had always told them she would be there for Pat as his future **guardian** and caregiver, they knew it was not realistic or fair to depend on her to fill their shoes. She deserved her own life with her young family.

With this realization, and after many conversations, we helped them build a team for Pat. Because Joe and Sarah had previously planned for family members to step in, and these family members, too, were getting older, they needed to replace them as

future caregivers for Pat. They selected a professional **trustee** for Pat's **special needs trust (SNT)**. Their daughter would be the family trustee to stay involved, but without the **fiduciary** obligations of a trustee. (This type of trust, also known as a supplemental needs trust, is used for a person with disabilities to supplement government benefits without jeopardizing the person's eligibility for benefits.) Joe and Sarah named their daughter a **successor guardian** and will help transition her into the role. But they identified backups for her to step aside if or when she is not able to continue. They collaborated with a caregiving agency provided from the state Department of Developmental Services (DDS), one they were familiar and happy with, for their son's PCA services. They began to build a team of caregivers by diligently interviewing candidates for various roles. DDS identified their high needs and supported their decision to have Pat move out of the family home before their deaths. When they moved Pat to his new home, some of the caregivers they had grown fond of were able to continue to provide care, which provided continuity and consistency for Pat, but also peace of mind for them.

Joe and Sarah set the framework and coordinated all the factors this book discusses: financial, legal, government benefits, emotional, and family support. They are still the captains of Pat's team. They host team meetings, which always include Sarah's delicious cooking, so that everyone knows one another as they begin to work collaboratively. They now plan to travel a bit, which seems like a luxury, but to others, it is a natural part of retirement. Sarah and Joe feel confident that others will be able to care for their son, and they feel very confident that when something happens to them, they have prepared both their children with the supports they will need to continue their relationship as brother and sister.

Stage V: Transitioning to the Next Generation—Your Team to Carry On

It may seem overwhelming at first, but take small steps toward creating your team. It will evolve and change over the various stages of your child's lifespan. Depending on your age and personal circumstances, it is best not to wait until a time of crisis to get others involved in your child's life. Just like planning to run a marathon, it takes time to prepare, warm up, and get started. You also might take some shorter runs to try it out before you build up to the big day. Once that day comes, the whole team will be in better shape to run the course.

We have been through the cycle of life with many families and have defined the process of creating a Team to Carry On over time. Circumstances may change, and your thinking about who is on your team may change at various stages and ages in you and your child's life, but it is important to get started. To build your Team to Carry On, you will need to:

- **THINK** about your options and possibilities for the members of your team: the who, what, when, and how.
- **ENVISION** the possibilities by identifying professionals, individuals, family, friends, and agencies you might want as part of your child's team. Ask them and coach them to prepare them for their role.
- **ASSIST** your team by connecting them and bringing them together at social and family events. When possible, invite them to join you for your child's individual support meetings, care plan meetings, or IEP meetings. We encourage successor guardians and **successor trustees**, personal or professional, to attend financial and legal planning meetings over time to get up to speed and stay current with what is expected and what the family values are to be carried on.

- **MENTOR** your team and monitor your plan by stepping aside periodically and bringing the team into your child's life.

There are several formal roles you play or have in place now that you will need to replace, as well as some informal roles that play a large part in the team, but which may not have a legal or formal title. The formal roles would be that of guardian or alternative option for guardianship, and the trustee(s) who would need to be named in your legal documents. The financial professional you want your team to use should be identified and named, either in your legal documents or in a **Letter of Intent (LOI)**, a document we will discuss further in Chapter 2. The informal roles would be case/care manager, an agency that provides supports, coaches, companions, social workers, and others who may be involved in your child's life.

Planning Pointer for Stage V: Communicate Your Plan

A combination of family members, friends, and professionals make a well-rounded team with checks and balances in each role. It is also important to think of successors to these roles in the event that a person is not able to continue doing what you expected them to do for your child.

Make sure you set them up to succeed. Talk with them about your expectations and listen carefully to theirs. Let them know about your plan and how it will support them in the role that they will play in your child's life. Introduce members of your team to one another when it is appropriate. Communicate your wishes by completing your LOI and by keeping it current.

SUMMARY: UNDERSTANDING THE PLANNING PRESSURE POINTS

In this chapter, we have created a roadmap for your child's future based on the five stages of special needs planning—early childhood, the school years, the transition to high school, the transition out of the school system and into adulthood, and finally, transitioning into the next generation to implement your Team to Carry On.

Each stage has its own unique planning needs. We have identified the various planning pressure points when you should be aware that there are changes in public benefits, services, and supports. We broke up the planning pressure points at each of the stages and ages to help you focus on what is important at different ages throughout your child's life. At each stage, specific actions are required of you to maximize public benefits, services, and supports. Once you are aware of what lies ahead, you will be better prepared for changes in each stage to plan accordingly.

We recognize that planning for individuals with disabilities can be overwhelming. Taking some time to create your own timeline of what lies ahead will build the foundation for your planning.

“The second edition continues to emphasize the ‘family’ in family planning, recognizing that every family is unique, that siblings may be the longest support for a family member with disability, and that a family member with a disability must have a meaningful voice in this process.”

—Michael L. Wehmeyer, Ph.D., Ross and Marianna Beach Distinguished Professor in Special Education,
Director, Beach Center on Disability, University of Kansas

“Financial planning for a loved one with a disability no longer needs to be an overwhelming, confusing, and often avoided topic. With this book, caregivers receive clear and practical advice for every step along the life journey. The time to start is now.”

—Brian Skotko, MD, MPP, Emma Campbell Endowed Chair on Down Syndrome,
Massachusetts General Hospital and Associate Professor, Harvard Medical School

How can families of children with disabilities plan for lifetime security? Find clear answers in *The Special Needs Planning Guide*, a step-by-step companion for parents navigating the complexities of planning for the future of their child and family. Written by two financial planning experts who are also family members of people with disabilities—Ron and James—this bestselling how-to guide is now in its second edition.

With clarity and compassion, the authors guide families in addressing five critical factors involved in special needs planning—**family and support, emotional, financial, legal,** and **government benefits factors**—at every stage of their child’s life. Throughout the book, readers will learn from the stories of other caregivers, get planning pointers and key questions to answer, and take action with the lists of Next Steps. To help families customize the information, the new edition also offers a **complete package of online resources**, including a fillable Special Needs Planning Timeline, financial planning worksheets, and a Letter of Intent template families can use to map out their vision for their child’s life.

Revised, reorganized, and updated to reflect current law, this book gives families the advice, strategies, and actions needed to plan for both their future and the well-being and security of their child.

WHAT’S NEW:

- Fully revised chapters and online resources
- A 10-step process that breaks complex planning into manageable tasks
- Letter of Intent now available as a fillable PDF
- Excel worksheets for easy planning
- New chapters on Foundational Financial Strategies and Tools, and Advanced Strategies and Special Circumstances
- Helpful information on ABLE accounts, housing options, and financial tips and tools
- New family learning goals, planning tips, and real-life case stories based on the authors’ experience
- Guidance on creating a Team to Carry On beyond the parents’ lifetimes

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