# 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 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 model that fits the needs of every family. There are, however, some basic guidelines and rules that can be applied to form a basis for a planning strategy.

## COMPARING TRADITIONAL FINANCIAL PLANNING WITH SPECIAL NEEDS PLANNING

When we first began speaking to groups of families, we learned that we had to clarify the distinction between planning for the needs of families that had a member with special needs and the needs of the typical family. The basic needs of both special needs families and traditional families overlap at various stages. The baseline needs of purchasing a home, saving for college, retirement, and estate distribution are similar in both special needs planning and traditional planning. In addition to these needs, families with special needs face additional challenges. Clearly, it is not recommended for families with special needs to adhere to the motto of "I'm spending my kids' inheritance." Having a child with special needs requires that families plan for two generations, because the child with disabilities may need parents' financial assistance and support into and throughout adult life. This is a common thread throughout this book.

There are any number of resources in the media, books, magazines, and newsletters available to raise awareness and education for the financial

**Excerpted from *The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life* by John W. Nadworny & Cynthia R.Haddad**

and legal planning needs of traditional families. Traditional families can find an answer to a basic planning question by calling in to a talk radio host, writing a letter to the financial editor in the local paper, 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.

In order to illustrate the differences between traditional planning and special needs planning, we have developed a special needs planning timeline (see Figure 1). This timeline 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 special needs planning timeline. Keep in mind that families with special needs 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 and/or benefits available. In addition, these are often the points in time when parents feel the pressure to begin planning. We identify these points as an indicator that action is needed, and these points 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. In later chapters, we provide strategies for the various stages of planning (pressure points) and discuss the Five Factors to consider for each stage, including family and support factors, emotional factors, legal factors, financial factors, and government benefit factors. We will then illustrate the issues and applicable planning stategies using actual case examples from families that we have worked with over the years. We recommend that families build their own personal planning timeline as they begin the planning process.

## THE KEY STAGES OF SPECIAL NEEDS PLANNING

We have developed a simplified approach to help families understand the complexities of special needs planning based upon our timeline of planning pressure points determined by the age of the child. Families have very little time to spare already but do indeed need the facts and figures to help them map a course of action to achieve financial security for themselves and their family. By reading the section that pertains to your child's age, you will get a quick overview of the basic points to consider and actions to be taken for that particular planning stage. By reading the entire book, however, you will get the detail necessary to develop an overall strategy for the future.

**Brookes Publishing | www.brookespublishing.com | 1-800-638-3775**

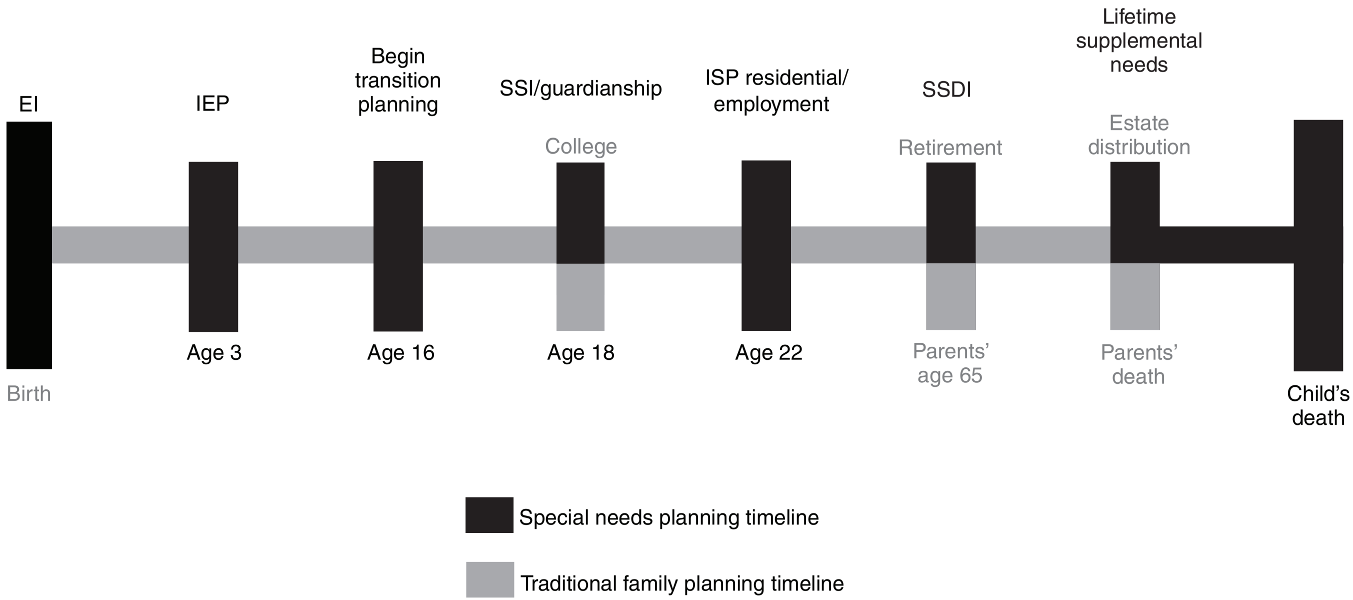

**Figure 1.** The special needs planning timeline illustrates all of the pressure points that individuals plan for. The distinction with special needs planning is that you must plan for the traditional family goals while incorporating the unique requirements of raising a child with special needs. (*Key:* EI = early intervention; IEP = individualized education program; SSI = Supplemental Security Income; ISP = individual service or support plan; SSDI = Social Security Disability Insurance.)

## Stage I (Birth to Child's Age 3)

If your child's disability is diagnosed between birth and age 3, the primary focus at that point is on understanding the diagnosis and obtaining early intervention (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- and community-based. Services can include diagnostic testing through hospital or school screenings 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 Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (see boxed explanation). Providing intervention services 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 PL 94–142, the Education for All Handicapped Children Act, now called the Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (PL 108–446) is the federal law for special education services. This law requires state and local education officials to provide appropriate special education services for eligible students in the least restrictive environment. See the web site for the Committee on Education and the Workforce at http://edworkforce.house.gov/nclb.htm for more information. Also see the U.S. Department of Education web site at http://www.ed.gov and the National Dissemination Center for Children with Disabilities web site at http://www.nichcy.org.

## Stage II (Child's Age 3—15)

When your child reaches age 3, the 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'04. This will begin with an assessment of your child's abilities and needs. Occasionally the 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 are required by law to do so. 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.

## Stage III (Child's Age 16—21)

When your child turns age 16, if you have not already done so, you should begin the transition planning 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. Your child's abilities are primarily identified, and his or her needs for future care both residentially and vocationally should be identified between the ages of 16 and 18. 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 upon your state of residence.

At age 17½, guardianship and/or alternatives to guardianship need to be addressed (see Chapter 4). 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. Inquire with your local chapter of The Arc, Autism Spectrum Disorders Support Center, Down Syndrome Congress, school special education parent advisory council, or other support agencies. Get on their mailing lists or visit their web sites (see the Bibliography section titled Web Sites to Investigate). Speak with other parents and share ideas—we all share the common thread of wanting what is best for our children.

Between the ages of 18 and 21 or 22, you will need to plan to insure that your child has a smooth transition into adult services. There are still many opportunities for higher education at age 18 to consider. 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, adult education, or vocational training); however, in addition to these considerations, parents will also want to focus on their independence. In fact, for some families *independence* is the primary focus. At this stage, understanding your child's rights and ensuring everything is in proper order is paramount to his or her 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 his or her own decisions. Physicians, educators, and service providers have no legally binding obligation to act upon your instructions on behalf of your child. This is where the issues of guardianship—or less restrictive alternatives to guardianship—need to be considered. (This issue is discussed further in Chapter 4.)

Also at age 18, your child may be eligible for Supplemental Security Income (SSI) based upon his or her own asset level. Although this is an entitlement program, your child needs to be eligible to receive these benefits. Basically, the individuals with disabilities cannot own assets in excess of $2,000 to qualify for SSI benefits. 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. The section in Chapter 4 on government benefits will provide greater details. In addition, you can visit the Social Security Administration web site at http://www.ssa.gov for further information.

## Stage IV (Child's Age 22 and Beyond)

Turning age 22 (or in some states, turning age 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 become a major challenge for many families. If you have not already done so, this is a critical time to better understand the state agency from which you may receive services. See the section on government benefits in Chapter 4 to learn more about locating the most appropriate state agency from which your child may receive services. Obtain as much information as possible about residential models and availability of services, and keep in mind that options do exist out there!

This is where the culmination of the efforts in your own personal planning, which you have hopefully initiated previously, 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 his or her life.

# Order Form

**BROOKES PUBLISHING** • P.O. Box 10624, Baltimore, MD 21285-0624

**ABOUT YOU** (write in your specialty and check one field that best applies)

Specialty ______

○ Birth to Five ○ K–12 ○ Clinical/Medical Personnel ○ 4-year College/Grad. ○ Comm. College/Vocational ○ Association/Foundation ○ Comm. Services

Name ______

Address ______

______

○ residential ○ commercial

City ______ State ______

ZIP ______ Country ______

E-mail ______

○ Yes! I want to receive e-mail about new titles and special offers. (Your e-mail address will not be shared with any other party.)

*We auto-confirm all orders by mail; please provide an email address to receive confirmation of order and shipping.*

| Qty | Stock # | Title | Price |
|---|---|---|---|
| | | | |
| | | | |
| | | | |

| | |
|---|---|
| Subtotal | |
| 6% sales tax, MD only | |
| 5% business tax (GST), CAN only | |
| P.O. customers: 2% of subtotal | |
| Shipping (see chart below) | |
| **Total (in U.S. dollars)** | |

PAYMENT METHOD

○ Check enclosed (payable to Brookes Publishing Co.)

○ Purchase Order attached (bill my institution)
*Add 2% to product total for P.O. handling fee

○ American Express (15 digits)

○ MasterCard (16 digits)

○ Visa (13 or 16 digits)

Credit card account number __ __ __ __ __ __ __ __ __ __ __ __ __ __ __ __

Security code (3 or 4 digit code on back of card): __ __ __ __

Expiration date __ __ /__ __ Signature ______

## Convenient ways to order:

**CALL** toll-free 1-800-638-3775 M-F, 9 a.m. to 5 p.m. ET.; **FAX** 410-337-8539;
**MAIL** order form to: Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624:
**ON-LINE** www.brookespublishing.com

**Money-back guarantee!** Ordering with Brookes is risk-free. If you are not completely satisfied, you may return books and videotapes within 30 days for a full credit of the purchase price (unless otherwise indicated). Refunds will be issued for prepaid orders. Items must be returned in resalable condition. All prices in U.S.A. dollars. Policies and prices subject to change without notice. Prices may be higher outside the U.S.A.

### STANDARD GROUND SHIPPING & HANDLING

(For other shipping options and rates, call 1-800-638-3775, in the U.S.A. and Canada, and 410-337-9580, worldwide.)

Continental U.S.A.** territories & protectorates†; AK, HI & PR‡

| For subtotal of | Add* |
|---|---|
| US$55.00 and under | $6.49 |
| US$55.01 and over | 12% |

***Continental U.S.A. orders ship via UPS Ground Delivery.*
*†U.S.A. territories & protectorates orders ship via USPS.*
*‡AK, HI, and PR please add an additional US$12.00. Orders ship via UPS Air.*
*Please call or email for expedited shipping options and rates.*

Canada

| For subtotal of | Add* |
|---|---|
| US$67.00 and under | $9.99 |
| US$67.01 and over | 15% |

*Orders for Canada are consolidated for shipping twice each month. For minimum shipping time, please place your orders by the 9th or 24th of each month.*

**calculate percentage on subtotal*