

The Guiding Star families need
for autism, ADD/ADHD,
psychiatric, developmental,
or special health needs



Family Road Map

A Step-By-Step Guide to Navigating Health,
Education, and Insurance Services
for Families with Special Needs

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A native Californian, she has lived for many years in Tennessee, where she served in leadership positions with her local and state NAMI (National Alliance on Mental Illness) affiliates and mental health/developmental disability policy councils. She also trained staff in High-Fidelity Wraparound for K-Town Youth Empowerment Network, a system of care for transition-age youth in Knox County, Tennessee.

Team Up for Families (TUFF) and Family Road Map Institute

This guide is adapted from *Team Up for Your Child* (2008, 2012) and *Road Map workshops* (2014-2016), created by Melton Hill Media, LLC, through its Team Up for Families initiative. TUFF Certified Trainers from Maine to Hawaii brought this guide and curriculum to nearly 500 family members in their own communities. In 2017, TUFF

leaders created the Family Road Map Institute, a training academy and learning portal dedicated to providing information and resources to families and agencies that serve children, youth, and young adults.

2017 Family Road Map Editorial Team

TUFF Collaborative members reviewed and provided editing assistance to transform the original *Team Up for Your Child* 2nd Edition text into *Family Road Map*: Kimberly Douglass, Associate Professor of the School of Information Sciences, University of Tennessee, Knoxville; Angela Lassiter, TUFF Administrative Lead; and Keva Clark,

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Welcome to the Road Map

Empowering the Journey to Help and Hope

When a child has serious problems, parents enter a strange new world. In this new world, most of the ordinary rules for raising kids don't seem to work. Something's wrong, but very often you don't know why or what to do. Friends and family give all sorts of opinions. It can seem like the tension around your house never quits. Who knows what's best? Who has the answers? How will you pay for this? Maybe you feel stressed out, angry, or just plain confused. Breaking down that confusion into manageable parts is what this book is all about.

If you are the parent of a young person with special needs, you tend to lose a lot of sleep. You worry about what will happen in the future. You worry about all the simple, fun things your child is missing. As time goes on, you may start to feel cut off from that other world of "normal" families whose lives have typical routines and whose kids seem to act in ways that other people understand.

You worry most of all about finding the right help, and that often means dealing with a lot of different providers. **Providers** is the term used in this book for the people and agencies who provide services for your child. Sometimes their language is filled with long, unfamiliar words. People with clipboards ask a lot of personal questions. You read forms, fill out forms, and sign more forms. It can feel overwhelming.

Team David: Our Road to a "New Reality"

At age three, our son David was diagnosed with autism. By age five, he was also diagnosed with bipolar disorder. For quite a few years, life in our house was tough. David would wake up from every nap screaming uncontrollably. Day after day, we coped with a child who suddenly exploded in a fit of scratching and biting. He didn't sleep through the night until he was five, and wasn't toilet-trained until age seven. He couldn't hold a real conversation until many years later. He spent a week in a psychiatric hospital. When my cell phone rang on a school day, it usually meant bad news. As he got bigger, life got scarier--and of course, we grieved for the "normal" life we couldn't have.

Little by little, something changed. We learned to reach out for help. With good treatment and the right support system, our son's functioning improved beyond anything we could have imagined. Today--in his 20s-- David lives independently in his own housing and takes care of everyday needs such as riding the bus, shopping, and cooking. He likes stocking shelves at a local store. He is passionate about collecting dinosaur figures, making short videos, and visiting natural history museums. We have a network of friends and helpers we call "Team David" who drop by on a regular basis. There are challenges, but all in all, things are good.

Through the years, our family learned ways to find support. Our job was to build a "new reality" that made sense for the life we live. To do it, we had to work as full, equal team partners with David's providers.



For All Kinds of Parents, Children, and Youth

The term "parent" in this book is meant to include grandparents, other relatives, legal guardians, adoptive parents, and foster parents who face the challenges of raising children or youth with medical, developmental, behavioral, and other complex health needs or learning differences. In some parts of this book, the term "child" is used, while in other parts, the term "child or youth" is used. This serves as a reminder that many of the strategies in this book apply to every age and stage of a young person's journey to wellness.



Welcome to the Road Map



**Those L-o-o-n-g,
Confusing Words**

*Medical, behavioral health, education, and insurance providers use a lot of technical language. For plain definitions of words printed like **this** in the pages of Family Road Map, see the Glossary, page 91.*

Symbols in This Book



Keywords and definitions of common terms you may encounter in dealing with providers, schools, insurance companies, and others



Family-tested strategies



Materials available in Spanish



Useful print resource



Important alerts



Lists or sample forms to fill in



Tips for taming paperwork



Try this



Useful online (website) resource



Tales from Team David



SET GOALS



Speaking Up

On this sheet, write down some things you want people to know about you. Everybody has things they like about themselves and their lives. Everybody has things they wish they could change. People in your life may already be asking you some of these questions. It's good to think about them on your own time, so you can say what you really mean. Your feelings and needs matter! Knowing what you want will make it easier to get the help you need.

**Ask for this page to be copied if you want to fill it out privately. This is your choice.*

My name is: _____

Some things I like to do are: _____

Things I like best about myself: _____

Things I worry about sometimes: _____

Things I do sometimes, but I don't know why: _____

If I could change something about my life or myself, it would be: _____

What really makes me feel good is: _____

In the future, I hope I can: _____

Step One: Consider Medical (Physical) Concerns

Check the conditions that have occurred “Never, Occasionally, Often, or Very Often” in the last six months.



	Never	Occasionally	Often	Very Often
1. Headaches				
2. Stomachaches				
3. Fever				
4. Dizziness				
5. Tires easily				
6. Sleeps much more than usual				
7. Sleeps less or complains of being unable to sleep				
8. Low energy				
9. Unexplained rashes				
10. Recent weight gain				
11. Recent weight loss				
12. Vision problems				
13. Hearing problems				
14. Ear infections				
Other Ailments:				



SUICIDE AND VIOLENCE RISK

If your child shows any of these signs:

- Sudden change in personality
- Gives away many favorite possessions
- Talks of wanting to die or “disappear”
- Takes unusual risks or shows reckless behavior
- Threatens suicide or violence
- Talks of family or others being “better off without me”
- Has a sudden and frequent interest in death or methods of dying
- Collects objects that may cause harm to self or others

TAKE IT SERIOUSLY. DO NOT DELAY. Seek immediate help from your doctor. In a crisis situation, call your local Specialized Crisis Services phone number. If you can’t find this number, call the nearest psychiatric hospital for information or call 911. Staff will come help you determine if your child needs emergency care. **See Guiding Star Point 5 for more on “Family Crisis Survival Guide.”**

Behavioral Concerns, continued

	Never	Occasionally	Often	Very Often
36. Says, "No one loves me."				
37. Has committed a crime.				
38. Feels guilty, thinks problems are "all my fault."				
39. Seems sad, lonely, or depressed.				
40. Is cruel to animals.				
41. Is physically cruel to others.				
42. Has trouble making friends.				
43. Has trouble keeping friends.				
44. Gets embarrassed very easily.				
45. Seems unusually shy with others.				
46. Is afraid to try new things due to fear of making a mistake.				
47. Lies to or "cons" others to get out of trouble, avoid things, or get things.				
48. Fidgets with hands or feet.				
49. Leaves seat at school or elsewhere when supposed to stay seated.				
50. Has difficulty waiting his or her turn.				
51. Interrupts others' conversations.				
52. Bullies or threatens others.				
53. Is angry and resentful.				
54. Acts on impulse.				
55. Defies adults or refuses to go along with requests and rules, despite possibility of punishment.				
56. Talks too much or too rapidly.				
57. Is easily annoyed by others.				
58. Blames others for his/her mistakes or behavior.				
59. Doesn't seem to listen when spoken to directly.				
60. Doesn't like to be touched.				
61. Skips school without permission.				
62. Has stolen valuable things.				
63. Argues with those in authority.				
Other symptoms:				

Sources: American Academy of Pediatrics, North Carolina Center for Children's Healthcare Improvement, National Initiative for Children's Healthcare Quality, NICHQ Vanderbilt Assessment Scale-Parent Informant. In: *Caring for Children with ADHD: A Resource Toolkit for Clinicians*. Elk Grove Village, IL; American Academy of Pediatrics; 2005. Additional source: "Pediatric Symptom Checklist" by Michael Jellinek, MD, and Michael Murphy, EdD, Massachusetts General Hospital, Boston, MA. Additional material from ADHD Checklist by Linda Zweifel, Director of Programs, NAMI Montgomery County, Texas; adapted with permission from author.

Step Three: Consider Developmental Concerns

Children develop at different speeds, but most gain certain skills at roughly the same ages. You don't have to be an expert to notice that your child seems to be developing more slowly or has very different behaviors from other children in the same age group. Developmental differences don't necessarily mean your child has, or will have, a disability. They may simply be signs that your child needs some form of short-term therapy. On the other hand, if a disorder such as autism is present, it is extremely important to diagnose and start services as soon as possible. In any case, if you feel uneasy about the way your child is developing, check it out. Here are some categories to consider (**Remember: These skills are compared with other children of the same age.** For example, few three-year-olds zip their own coats, but most six-year-olds can.)

Sensory Processing: How does the child learn best—by seeing, hearing, smelling, tasting, or touching? How does this affect daily life? _____

Sensory Modulation: Does he/she seem to react too much or not enough to sounds, touch, or light? Do rough clothes, new shoes, or shirt tags make him/her unable to concentrate? Does he/she avoid certain "normal" sensations or seek them out? _____

Communication: When did your child begin to babble? Speak in words? String words into simple sentences? Does your child (above age 2) use back-and-forth talk with others? Use conversation to ask for things and information? _____

Social Skills: Does he or she form attachments easily with close relatives or friends? Get along in groups of same-aged children? Seem to understand and be able to play games with rules? Understand what others are feeling and signaling by their actions? Understand body language? _____

Emotional Modulation: How well does the child handle changing emotions and moods? Is he/she generally happy and calm or often agitated and irritable? Easily affected by noisy or hectic situations? How well does he/she put up with frustration? Can he/she calm herself independently after getting upset? _____

Cognitive Ability: How easily does your child learn things compared to others his/her age? Which types of learning (for example, numbers and math, language or reading) seem hardest for him/her? _____

Motor Skills and Planning: How well does the child move "in space" compared to other children of the same age? How well does he/she run? Does he/she have trouble with skills, such as tying shoes or zipping a coat? Can he/she carry out tasks that include several steps? _____

Behavior Log

Behavior Log for: _____

Medications: _____

Log begun (month, day, and year): _____



Date	What happened, or what was the behavior?	Where and when did the behavior take place? (Example: At school, during recess, while doing homework.)	What was taking place right before the behavior happened? (Example: Change in family plans, child told "no" about something he wanted, argument with sibling.)	Other comments, details, or factors involved? (Meds change? Illness? Event in family?)	What happened AFTER the behavior took place? (What actions did you, the child or youth, or others take?)

Dealing with Treatment Bills and Benefits

4.2: Insurance. When your child or youth has a problem, the goal is simple. You want to find the best help, as quickly as possible, at a price your family can afford. However, in our American healthcare system, the path to that goal is far from simple. A lot depends on your child's or youth's insurance benefits. Benefits are payments made by an insurance company for services your child or youth receives. The rules for getting that treatment can be complicated. That's why you must work with health, behavioral health, and insurance providers to make sure your child or youth gets the benefits he or she needs.

Imagine a giant office building that contains every sort of treatment your child or youth and family can receive. Imagine that inside the different offices of this building are all the organizations that provide treatment, as well as all the providers who work for these organizations. This giant building would have three front doors that might be marked with the following signs:

1. **Door #1:** No insurance or not enough coverage for the treatment your child or youth needs
2. **Door #2:** State-sponsored health insurance
3. **Door #3:** Private insurance through a health exchange or employer

Each door leads to a different series of hallways and other sets of doors that you (and your paperwork) will have to pass through to be able to pay for some type of service.



Behind Door #1, if your child does not have insurance **coverage**, or your child's plan does not cover a certain type of treatment, or you can't afford to pay your part of the cost, you may be able to use free and low-cost **community resources** such as **prescription drug assistance programs**, county health clinics, or clinics that charge on a **sliding scale** (according to what you can pay). To learn about finding low-cost resources for uninsured families, or how to apply for benefits under Medicaid programs, go to Centers for Medicaid Services, www.cms.gov. Local community programs may be able to help you fill out the forms.

To search for local resources, you can also **call "211" or go to www.211.org** and put in your zip code. You can also call your county health department to find out about low-cost resources.

You may need to fill out applications and visit government agencies or community programs to see if your child is eligible for free and low-cost insurance programs that help families who are uninsured, low-income, or have big medical bills. **In most cases, your child will qualify to get state-sponsored insurance if you can't afford a private policy** (even if you and other adults in the house are not eligible).



DOOR #1

No insurance plan or not enough coverage for the treatment your child or youth needs

This means you pay directly for your child's care or get help from free and low-cost services such as the health department (for some services).

Glossary

A

Accommodations and modifications. Changes made in a regular education program to help a child or youth make educational progress. Certain criteria must be met to be eligible for these changes (see 504 Plan).

Acute. Symptoms that are both temporary and severe.

Affected child. A child who shows symptoms of a behavioral health or other disorder.

Agenda. A document, which lists the main points to be covered in an IEP meeting.

Annual (IEP) goal. An educational goal that the school system expects your child or youth to reach by the end of a year, as part of his or her Individualized Education Program (IEP).

Annual IEP review. A meeting to review a child's IEP and make any necessary changes in goals, services, or placement within the next year.

Annual or lifetime maximum benefit. The maximum amount that your healthcare plan will pay for treatment of a particular kind of health problem, either per year (annually) or during the entire time your plan is in effect.

Annual out-of-pocket maximum. The maximum amount that you will be required to pay per year for certain types of treatment under the terms of your health insurance plan.

Appeal. A formal request for a decision to be changed by a higher authority.

Areas of need. Broad categories in which your child needs to improve in order to make progress in school, as determined by the IEP team and included in the IEP document.

Assess. To evaluate a person's medical, behavioral, or educational condition in order to determine what services the person needs.

Assessment team. A team of school staff or consultants assigned by the school to evaluate a child. For behavioral health issues, the team usually includes a psychologist and may include specialists in certain disorders.

At-risk. In possible danger, especially for developing a problem.

Authorize, authorization, pre-authorization, prior authorization. Approval given by the insurance company for a treatment that is shown to be medically necessary and covered by the person's health care benefits.

B

Behavioral Health Organization (BHO). An insurance company that manages benefit plans for mental (behavioral) health or substance (drug and alcohol) abuse treatment.

Benefits. Also called "coverage." The contract between an insurance provider and the insured person that obligates the insurance company to pay for certain medical or behavioral health treatments.

Black-box warning. A Food and Drug Administration (FDA) warning that alerts doctors to a possibly serious side effect or complication that might be caused by giving a medication under certain conditions.

C

Care manager. A type of case manager for a health insurance plan whose job it is to help people find options for getting treatment approved or to solve unusual problems with the benefits plan.

Case manager. A staff member in a medical, behavioral health, education or insurance setting, whose job is to set up services, coordinate services, or help solve problems for a client.