

**YOUR CHILD'S
DIAGNOSIS**



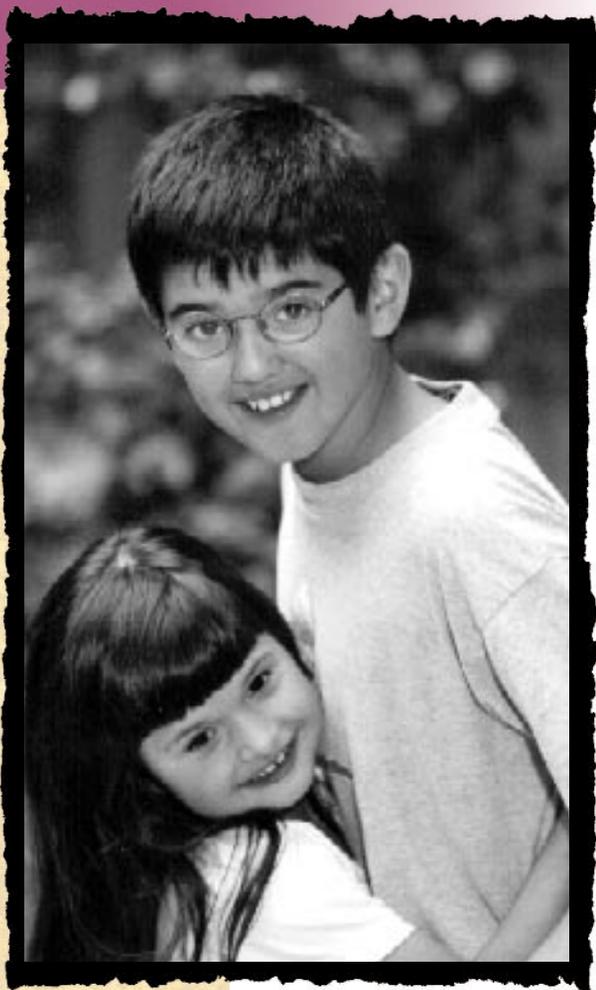
MAKING THE

YOUR CHILD'S DIAGNOSIS...

Your child has recently been diagnosed.

You'll want to discuss this diagnosis with an appropriate professional – a physician, neurologist, psychologist, developmental specialist, occupational or physical therapist, or a speech and language specialist.

If you haven't contacted someone yet, contact the appropriate specialist as soon as you can. If you need help in finding or selecting a professional to talk to, the people at Harbor Regional Center can help you.



The Harbor Regional Center Clinical staff includes a physician, psychologists, an occupational therapist, a speech and language specialist, nursing consultants and other clinical specialists.

Your child's Counselor can arrange a time for you to meet with any of these specialists to help you understand diagnostic information. Your child's Counselor can assist you with a referral to another professional for this consultation.

THREE KEY PIECES OF THE PUZZLE...

This booklet provides you with some information on three key pieces of the puzzle that will make all of the information to follow more useful for you, your child, and your family.

These three key pieces of the puzzle are:

► **Identifying my family's values**

These are not the "family values" you hear politicians talking about every election year. These are the values that your family holds dear, that guide you in the pursuit of the life you want for yourself and your family. These are very personal, very individual – the values that you select.

► **Developing your ability to objectively observe and report your child's development**

The people working with your child rely on the information you provide in order to design the best possible intervention plan for your child. They need accurate information to design a plan that matches his strengths and needs. This plan will be improved by the quality of the information you provide them.

► **Developing your ability to evaluate information and information sources**

So much information is available that this can become an overwhelming task. One website alone has links to 763 other sites on autism spectrum disorders and related subjects. When you can evaluate information and information sources, you'll be able to quickly decide how useful a source of information is to you.

IDENTIFYING MY FAMILY'S VALUES...

Throughout our lives each of us will be faced with many choices, with many opportunities for decision-making. How do we make good choices?

No one can tell you what is the “right” choice for you. Only you can decide that. “Good choices” match your values.

The best choice for your neighbor may not be the best choice for you, even when the circumstances are very similar.

Good choices are based on your personal values and your family's values.

If you don't share the same values – then the choices you make should be different.

Let's say your neighbor places a high value on wealth, then he might want to drive a car that symbolizes “having wealth.” Maybe you place a high value on family, then you would want to drive a car that has accommodations for a large family.

Once you have decided what you want your life to look like, you will be purposeful in making good choices.

Many successful people credit a great deal of their success to visualization exercises that include “seeing themselves succeed,” whether this is sinking a putt, hitting a home run, running a business, or managing their personal life.

Knowing what you want your life – and your child's life – to look like will help you better understand where you are now. It will also help you to make sure that the steps you take are always in the right direction.

This is true in sports, in running a business, or in managing your life.

It's also true with parenting. In order to handle the number of choices you will face throughout your child's life, you need to first decide which values are most important to your family. Decide what “end” you have in mind.

You want to keep this end clearly in mind as you make daily choices.

How can we make sure that we spend our personal resources – time, energy, and attention on the things that really matter to us?

Our modern world can be a very busy place to be. Every day we are faced not only with many choices, but with many pressures and deadlines.

Every one of us has many demands on our personal resources – including our time, our energy, our finances, even our hearts and minds.

It can be far too easy to get caught up responding to these multiple demands for our attention and find ourselves with no resources left for what's important.

External demands on your resources, those that come from outside yourself, can seem urgent.

With preparation you'll find that you can make everyday choices based on what's really important to you and to your family.

When you make choices based on your personal values – you are doing what's really important, instead of what is merely urgent.

Since good choices are based on knowing your personal values, we've developed a **Value Table** (located at the back of this booklet) to help you determine your family's values.

Complete this with your family – your spouse, your significant other, your other children, your parents, your in-laws – whoever supports you in raising your child.

Do you think you'll agree on every value? Probably not, but that's not necessary.

Rate each value listed either “Never” for those values you don't want in your life; “Seldom” for those values that are not usually important to you/your family; “Often” for those values that are usually important to you/your family; or “Always” for those must-have values that are very important to you and your family.

Don't do anything with the last column, marked “Priority,” for right now.

The more quickly you do this, the more instinctive and heart-felt your choices will be.

Next, take the values you've marked "Always" and select the eight values that are most important to you, marking only those eight in that last column, "Priority."

When you have selected your eight values, write them in the spaces below.

My top eight values

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

These are your family's top values, those values that you feel are most important to you in making decisions for your child and your family.

These are the values you will consider every time you need to make a choice about supports or services for your child – or any other major decision for your child and family.

Of course, you may want to do this activity again as your situation changes.

REPORTING YOUR CHILD'S DEVELOPMENT...

Now that you've identified your family's values, you're ready to develop a plan for your child.

Whether you are working with a developmental specialist, an occupational or physical therapist, a speech and language specialist, or any other specialist, the information you provide at the first planning meeting is important.

The initial plan for your child will be based primarily on the information you provide about your child's strengths and needs.

This is why the specialists need to ask you so many questions.

Once the intervention plan is begun, there will be opportunities for the people working with your child to provide their own observations as well, and adjust the plan as necessary.

Here's a story to illustrate this:

Suppose that you've just discovered that you have a winning lottery ticket. However, to claim your prize you must present the winning ticket to an office in Sacramento within two weeks.

You realize you don't know the city or even the county in which you're standing.

Because you don't know your present location, your choices are to remain where you are, hoping to be discovered, or to begin walking in one direction or another.

You need to know where you are starting from and have a reasonable set of directions to lead you to Sacramento.

Without these, you may eventually get to Sacramento, but long after the lottery office is closed and your winnings are being spent by someone who knew where he or she was and had a clear set of instructions to get there.

To get what you want, you need to know where you are, where you want to go and have a clear idea how to get there.

The people working with your child need the best information possible about where your child is starting from in order to help your child move directly toward the goals you've identified.

Parents have a unique role in the planning process. You are the best expert on your child.

You spend hours every week in the company of your child, making observations in a variety of situations.

You have specialized knowledge about your child and have the opportunity to notice small but important changes that may be overlooked by others.

Think back to the last time you took your child to a doctor. You provided the doctor or nurse information about his symptoms and general health.



They asked you for your observations, because you are familiar with your child.

When health care professionals diagnose and treat children, they gather information from different sources. Your observation of your child is one important source of information.

To diagnose and design a treatment plan the doctor also needs some objective information, such as tests and measurements.

Good treatment planning includes both your observations about your child's strengths and needs, and some objective information from various tests and measurements.

This method can help in designing a treatment plan for your child. Your observations will again be important for follow-up assessments.

The treatment plan should include ways for parents to collect and report their observations about their child's progress:

- ▶ Is the plan working?
- ▶ What works and what doesn't?
- ▶ Could it be improved?
- ▶ What more or different is needed?

The **Questions to Ask Yourself** (at the back of this booklet) will help you when you make and report observations about your child's strengths, needs and progress.

EVALUATING INFORMATION...

Information is neither good or bad. The issue is how useful it is for you and your needs at a particular point in time.

You are reading this booklet because you want to know how you can help your child to become the best individual he or she can be.

There is so much information available right now – on this topic and related topics – it can be hard to decide what to read or who to listen to, what to believe, what advice to follow.

You want to develop the skills to evaluate information as quickly and accurately as possible.

Some areas to consider for your first look at any new information are:

▶ **Author**

What are her credentials? Does his educational background, writings, or experience indicate he knows the topic? Is she associated with an institution or organization? What are the basic values or goals of the organization or institution?

▶ **Date of publication**

When was this published? Is the source current or out-of-date for your topic? Topic areas of continuing and rapid development demand more current information. On the other hand, in the humanities, material that was written many years ago can remain helpful.

▶ **Edition or revision**

Is this a first edition of this publication? Further editions can indicate a source has been revised and updated to reflect changes in knowledge, and include omissions. Many printings or editions may indicate that the work has become a standard source in the area and is reliable. If you are using a Web source, do the pages indicate revision dates?

▶ **Publisher**

If the source is published by a university press, it is likely to be scholarly. Although the fact that the publisher is reputable does not necessarily guarantee quality, it does show that the publisher may have high regard for the source being published.

► **Title of journal**

Is this a scholarly or a popular journal? This distinction is important because it indicates different levels of complexity in conveying ideas.

...and some areas to consider about the content are:

► **Intended audience**

What audience is the author addressing? Is the publication written for a specialized or a general audience? Is this source too simple, too complicated, or just right for you?

► **Objective reasoning**

Is the information given fact, opinion, or propaganda? It is not always easy to separate fact from opinion. Facts can usually be verified. Opinions – though they may be based on facts – are the author's interpretation of facts. Skilled writers can make you think their interpretations are facts.

Does the information seem true and well-researched, or is it questionable and unsupported by facts? Assumptions should be reasonable. Note any errors or omissions. Is the author's point of view objective and impartial? Is the language free of propaganda – emotion-rousing words and bias?

► **Coverage**

Does the work bring up-to-date other sources, agree with other materials you have read, or add new information? How well does it cover your topic? Explore enough sources to get a variety of viewpoints.

Is the material first or second-hand in nature? Primary sources are the raw material of the research process. Scholars use this primary material to help generate interpretations – a secondary source.

► **Writing style**

Is the publication organized in some clear and logical way? Are the main points clearly presented? Do you find the text easy to read? Does the author repeat himself?

► **Evaluative reviews**

Locate critical reviews of books in a reviewing source, such as Book Review Index, Book Review Digest, or Periodical Abstracts.

Is the review positive? Is the book under review considered a valuable contribution to the field? Does the reviewer mention other books that might be better? If so, locate these sources for more information on your topic. Do the various reviewers agree on the value of the book or do the reviews lead to more questions?

For Web sites, try consulting one of the *evaluating and reviewing sources on the Internet*.

The following pages provide a shortcut for making these evaluations quickly and accurately.

Use some of the resources from the reading, viewing, and on-line resource lists for practice.



QUESTIONS TO ASK YOURSELF WHEN RECORDING YOUR OBSERVATIONS

► Are my observations objective?

Observe and report what you see without judging, generalizing, or interpreting what happens. When you are objective you report what happens without any personal filters that might influence you. Factual, non-judgmental notes will help you recall your child's activities.

The best way to make sure that your observations are objective and non-judgmental is to report specifically what you see. Use verbs, adverbs and adjectives that describe your child's behavior.

► How specific is the information?

Record and report in as much detail as possible. Exactly what did your child do, for how long, where and when?

Was the observation made when he was playing alone, in a small or large group, with people he knows well or with strangers? It's best to record several observations, in different places and at different times.

► Are my observations direct?

Report what you see, not what is reported by others. Primary data includes only observations that you make describing events. Relating what others have said they saw is more often misleading.

Once you have an intervention plan with clearly identified goals for your child, you may find it useful to make a checklist-style format to help you collect your observations as they occur.

► Is my information complete and inclusive?

Describe the event from beginning to end. Include who was involved, what action occurred, when and where the action took place, how the action occurred, and how others reacted to your child.

Be sure to include your child's strengths, as well as any changes in circumstances that may affect your child's progress. Keep track of your child's progress – follow his successes, note any failure.

QUESTIONS TO ASK WHEN EVALUATING INFORMATION

► How factual is the presentation?

The best argument is one that supports its theory with relevant, accurate, and up-to-date information from the best sources possible. Is the author believable, how recent is the material, what research (if any) supports the positions, and what documentation is behind any argument?

► What is fact? What is opinion?

A fact is a statement that can be proven. An opinion expresses how a person feels about an issue or what someone thinks is true. Many authors blend fact and opinion. Many opinions make good sense and may win an audience's approval. They must still be classified as opinions if there is no factual evidence supporting them. Opinion may be entirely correct, but generally it still should be viewed with less trust than facts.

► What propaganda is being used?

Propaganda is information presented in order to influence the audience. It is not necessarily "good" or "bad." Many authors purposely use propaganda in order to convince their audience of their point of view. A close look at the author's background or the source of the publication may provide clues about what propaganda might be used.

► What cause and effect relationships are proposed?

A lot is written to support a theory that something "causes" an "effect" to happen. Experiments are often a search for cause and effect relationships. To evaluate information you must note when an issue has at its heart a disputed cause and effect relationship. Isolate the claim and examine the relationship for yourself.

► Are these cause and effect relationships merely correlations?

Many cause and effect statements are flawed because no research or evidence has isolated a single cause. There may be other hidden factors underlying the relationship.

► Is the information distorted?

Many authors, to support their position, quote statistics and research that support their viewpoint. All of these statements of facts may be biased. Always question the bias involved in obtaining and presenting data. Tabulated numbers or graphs may only reflect opinions.

► Are analogies faulty?

Authors use analogies to support their theory. An analogy is a comparison of an unproven theory to a known set of causal events. However true the second part of the sentence may or may not be, it should not necessarily be accepted as a demonstration of the truth of the first part of the sentence.

► Is the author oversimplifying the issue?

Authors generally try to show their theory in the best possible light and to discredit opposing viewpoints. When authors are so single-minded as to completely ignore opposite viewpoints, they may oversimplify.

► Is the author stereotyping?

This sort of logical flaw is similar to the cause and effect flaw. The authors may have observed some general behavior, then attempted to apply this general behavior to a specific individual or situation. Each point should be evaluated individually, not grouped with other observations.

► Are there faulty generalizations?

In the case of a faulty generalization, a judgment is based on inaccurate or incomplete information. For example: "Ducks and geese migrate south for the winter; therefore, all birds migrate south for the winter."

VALUE TABLE

VALUE	Never	Seldom	Often	Always	Priority
Acceptance					
Accepting things as they are					
Achieving all one can					
Advocating for rights and services					
Balancing attention to family members					
Being a valued member of the family					
Being accepted by others					
Being creative					
Being healthy					
Being helpful to others					
Being honest					
Being interdependent					
Being like everyone else					
Being loved					
Being self-reliant					
Being the best "me" I can be					
Being treated with dignity and respect					
Being with non-disabled people					
Collaborative decisions					
Complete safety					
Continuing to learn					
Contributing to my community					
Creating change					
Delegating decisions to others					
Don't ask for help					
Embracing diversity					

VALUE	Never	Seldom	Often	Always	Priority
Equality of opportunity					
Equality of results					
Excellence in service					
Facing limitations openly and realistically					
Family					
Feeling good about oneself					
Focusing on gifts and strengths					
Following through					
Getting along well with others					
Getting professionals to do their jobs					
Good health					
Greater independence					
Having a plan					
Having "alone" time					
Having choices					
Having friends					
Having fun					
Having others like me					
Having people accountable for results					
In control of one's life					
Keep it in the family					
Knowing my child is safe					
Knowing my child will be taken care of					
Learning new skills					
Life plan					
Living life on one's own terms					
Loving and being loved					

VALUE	Never	Seldom	Often	Always	Priority
Making good choices					
More options					
Parents know best					
Peace of mind					
People with disabilities in the community					
Promoting inclusive educational services					
Reaching one's full potential					
Reasonable safety					
Respected for who I am					
Seamless service system					
Self-determination					
Smooth-running programs					
Solving my own problems					
Staying connected to family					
Strong spiritual life					
Taking care of your own					
Taking risks					
Teachers know best					
Trusting professionals to do the job right					
Trying new challenges					
Working as a team					

(Other, specify)



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