THE PARENT PERSPECTIVE

Laura J. Warren
Sherry Santa
Texas Parent to Parent

Who We Are

Parents of children with disabilities, chronic illness and other special health care needs (including preemies)

Small staff of full- and part-time employees (24) and many volunteers (need MORE!)

Many years of experience providing parent-to-parent support

Statewide nonprofit (§501 (c)(3)) headquartered in Austin

Our Goals

- increase the confidence, emotional stability and skills of families
- provide a place where families can get answers to specific questions
- increase families’ knowledge and access to resources

- decrease stress and isolation
- help families find or create resources for support
- provide technical support to families or parent groups

What We Do – Connect Families

Match parents (if requested) for emotional support or information

Provide trainings (ex: transition, advocacy, resources, Medicaid waiver programs, people first language, etc.)

Statewide Parent Conference: June 21st and 22nd, 2019 in San Antonio

Three One-Day Conferences: Tyler February 23rd, 2019, Amarillo March 30th, 2019 and RGV in the Fall.

Listserv for parents and family members: regional areas & issue/ disability specific & now professionals)

Resource Directory

Quarterly Newsletters

TxP2P Volunteer Opportunities

- Medical Education Program (MEd)
- NICU Network Support
- Peer Parent Mentor Program (PPMP)
- Texas Advocacy Network (TAN)
- Pathways to Adulthood (PTA)
- Help at HQ (Austin) – interns welcome!

“....No man is an island, entire of itself...”

--*John Donne* (1572-1631)

Who We Serve

- Over 7,000 families
- All ethnicities & races
- All sexual orientations
- Spanish-speaking families
- Undocumented families
- All political parties

PARENT
COMPANION
FIRST FIVE YEARS

http://www.parentcompanion.org/

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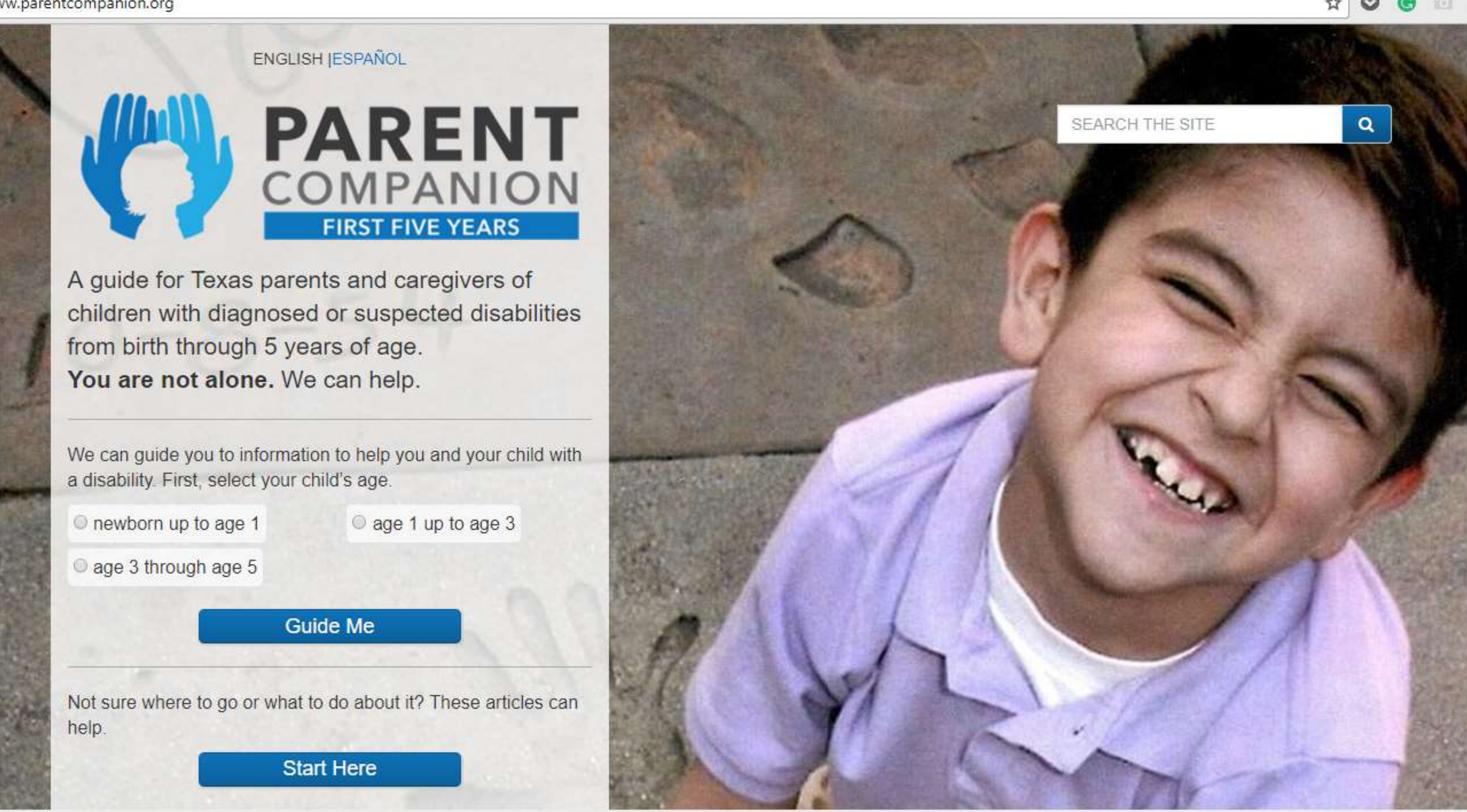


A guide for Texas parents and caregivers of children with diagnosed or suspected disabilities from birth through 5 years of age.
You are not alone. We can help.

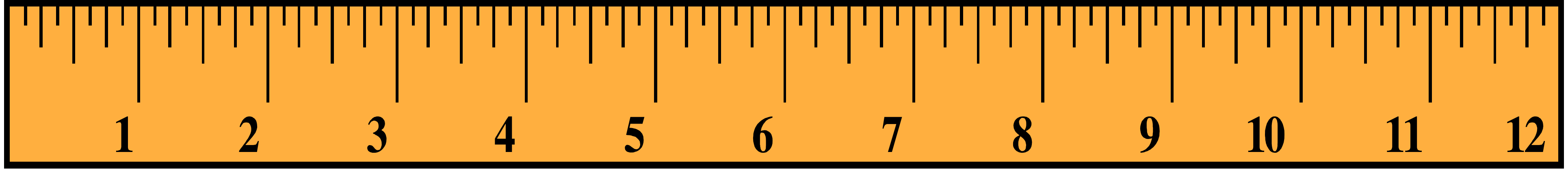
We can guide you to information to help you and your child with a disability. First, select your child's age.

○ newborn up to age 1
○ age 1 up to age 3
○ age 3 through age 5

Not sure where to go or what to do about it? These articles can help.

Grief

The Five Stages of Grief
According to
Elisabeth Kubler-Ross
From her book “On Death and Dying”



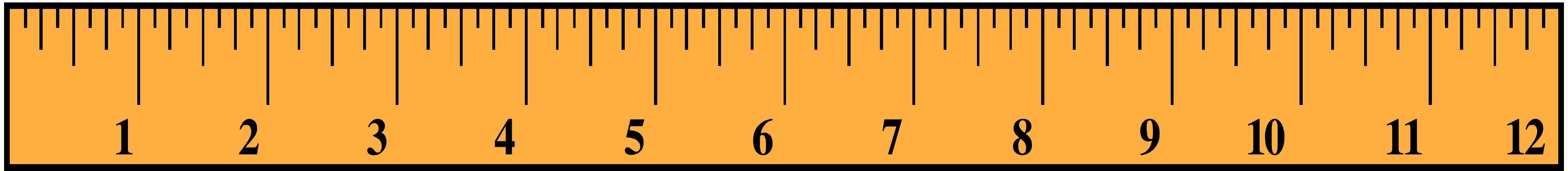
Denial

Anger

Bargaining

Depression

Acceptance



Dr. Kubler-Ross identified other feelings associated with Grief!

- Numbness
- Sadness
- Guilt
- Fear
- Anxiety
- Physical Illness
- Feeling Victimized
- Confusion/Disorientation

Grieving Process for Families of Children with Disabilities or Chronic Illness!

According to Ken Moses, Ph. D.

Parents generate core level dreams for their children even before the child is born. Disability shatters those dreams. Grieving is the process whereby parents separate from those shattered dreams and begin creating new dreams.

The Grieving Process:

- It’s an unlearned, automatic feeling process.
- It must be shared with a significant other.
- It may be a reoccurring cycle.
- Grieving is not an accepted state by society or sometimes even by the bereaved individual, either in specific or general.
- Grieving brings out the feeling states of denial, anxiety, fear, guilt, depression and/or anger.

The Feeling States

Fear:

Fear brings out the issue of fight or flight. The flight takes you into denial and fight gives you the energy to reattach and generate new dreams.

Denial:

Denial buys time to get you ready to deal with the loss, to prepare to deal with the issue of the disability, to find inner strength and external supports.

Guilt:

Guilt helps people determine what they have control over and what they do not. "Do my actions, thoughts, and beliefs make an impact on what happens to me?"

Depression:

Depression helps you redefine what it means to be a competent, capable, valuable, and strong person. You can feel depression without being depressed.

Anxiety:

Anxiety mobilizes and produces the energy needed to make necessary changes.

Anger:

Anger generates considerable energy to help you begin the necessary changes in your life.
It eventually leads you to identify the misconceptions and the truth about fairness and justice.

It may be a reoccurring cycle!

FOUR STAGES OF ADAPTATION

Surviving

Searching

Settling in

Separating

"Nobody's Perfect - Living & Growing with Children Who Have Special Needs" Nancy B. Miller, Ph.D., M.S.W., adapted by Laura J. Warren, Pilot Parent, Arc of the Capital Area)

SURVIVING:

What you do to keep going when you are feeling completely overwhelmed because something totally out of your control has taken away your child's equal chance at life.

You have something new and frightening to deal with, and you have to begin adapting to an uncertain future.

TYPICAL REACTIONS TO SURVIVING

- **Shock**

- **Bodily Stress & Symptoms**: fatigue, physical symptoms (headaches, stomachaches, chest pains, loss of appetite, lack of sexual interest, etc.), feelings of weakness, fragility, and vulnerability

- **Grief and Loss**: grief, feelings of helplessness & aloneness, sadness, depression

- **Confusion and Fear**: confusion & chaos, uncertainty & ambiguity, fear, preoccupation with your child, worrying, asking questions that appear to have no answers

TYPICAL REACTIONS TO SURVIVING

(CONTINUED)

- **<u>Guilt and Self-Doubt</u>**: guilt, self-absorption, self-pity, & self-doubt, shame & embarrassment
- **<u>Anger</u>**: resentment & envy, blaming, feelings of betrayal
- **<u>Denial</u>**: chosen denial, unconscious denial

“Being in a state of Surviving doesn’t last forever.

It just seems that way at the time.”

SEARCHING:

Google

What you do when you are looking for answers for your child. You will probably have periods of searching during your whole life with your child.

There are two kinds of searching:

<u>Outer Searching</u>: looking for a diagnosis or services

<u>Inner Searching</u>: trying to find your identity as the parent of a child with special needs.

SEARCHING is a time of acting, of moving forward from your reactive stage of *Surviving*.

It is the awakening of a sense of control over your emotions and your life, and a time for seeking understanding about your child, your family, and yourself.

SETTLING IN:

What you do when the frantic pace of searching lets up. You begin to choose your battles and balance your child's schedule and your family life. Not only has your outer searching subsided for a while, but more important, your attitude about it settles down.

Settling In is seeing the world for what it is and seeing yourself for who you are. It is moving beyond the intense emotions of *Surviving*, feeling less of the sense of urgency of *Searching*, and gaining a greater sense of control and balance in your daily life.

SOME FAMILIES ARE NOT ABLE TO ENJOY THE NORMALITY OF FEELING SETTLED IN OR THIS STAGE MAY BE DELAYED, DUE TO THE FOLLOWING OBSTACLES:

- ✓continued medical crises or aggressive/self-destructive behaviors or the physical or mental health of any family member
- ✓lack of financial resources or insurance or adequate insurance
- ✓severe medical, learning, emotional, or behavioral problems; needs that families are not able to meet at home
- ✓a marriage or relationship that cannot weather the storm
- ✓single parenting resulting in juggling all the responsibilities
- ✓old *Surviving* or *Searching* issues that come back into the foreground

SEPARATING:

What you do as a normal, gradual process that occurs in tiny steps throughout childhood.

When a child has a disability, the process may need to be altered or slowed down.

Extra parenting may be required - you may have to initiate separation, plan it, find it and make it happen.

OBSTACLES TO SEPARATING

<u>Child-Related Obstacles</u>: special communication needs, social skill or safety issue

<u>Parent-Related Obstacles</u>: concerns about how much to protect or pull back, time or support team issues

<u>Community Obstacles</u>: lack of programs, lack of services or resources - funding, lack of transportation or scheduling problems, negative or hesitant attitudes in community

“You don’t recover from the events of life, you take them with You, you knit them in, you grow with them and around them; they become who you are; they are life itself; how else my life might have been is unknowable; and the truth is , I wouldn’t change it for any other.”

From Charles L. Mee’s book,
A Nearly Normal Life, A Memoir

Attitudes Required to use Active Listening

Active Listening is a method for putting to work a set of basic attitudes.

Without these attitudes, the method seldom will be effective: it will sound ….

FALSE

EMPTY

Mechanical

Insincere

1. You must want to hear what the parent has to say.
2. You must genuinely want to be helpful to the parent.
3. You must genuinely be able to accept their feelings.
4. You must have a feeling of trust in the parent's capacity to handle their feelings.
5. You must appreciate that feelings are transitory, not permanent.
6. You must be able to see the parent as someone separate from you.

Roadblocks to Listening

Ordering

idiculing

Warning

Questioning

Commanding

Instructing

Shaming

Directing

Interpreting

Interrupting

Psychoanalyzing

Threatening

Preaching

Admonishing

Judging

Diagnosing

Exhorting

Advising

Blaming

Moralizing

Criticizing

Humoring

PEOPLE FIRST LANGUAGE

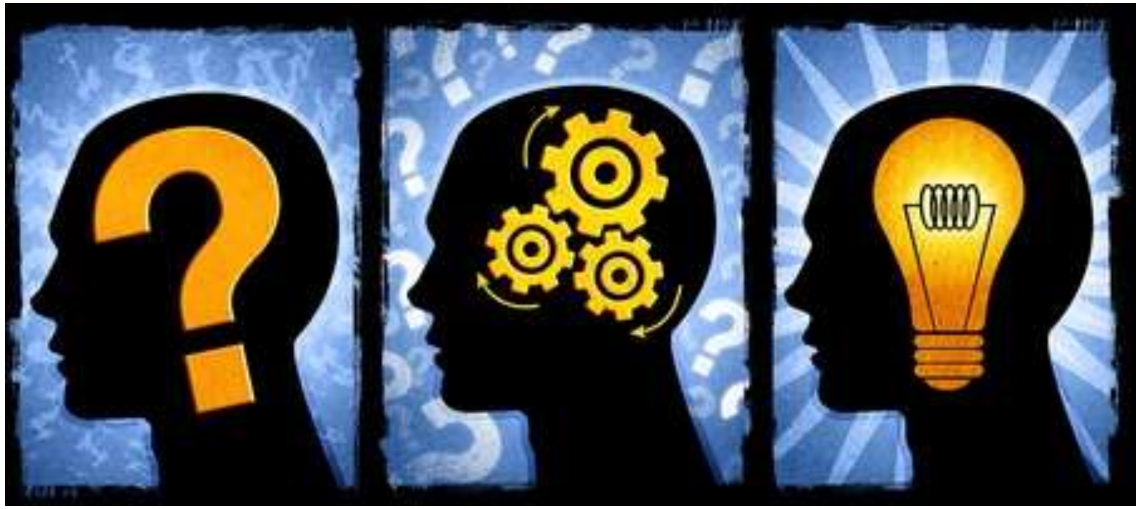
If thought corrupts language, language can also corrupt thought.

- *George Orwell*

IF YOU CHANGE WHAT PEOPLE SAY...

You can change what people think

And change what people do!



WORDS MATTER!

They…

- eliminate stereotypes
- shape our thoughts and actions

WHO ARE PEOPLE WITH DISABILITIES?

- Mothers
- Fathers
- Children
- Friends
- Neighbors
- Relatives
- Teachers
- Plumbers
- Legislators

PEOPLE WITH DISABILITIES:

are “regular” people

have common goals

are more like everyone else than they are different

"People with disabilities are people, first . . . People First Language says what a person ***has***, not what a person ***is***. It puts the person before the disability."

-Kathie Snow

USING PEOPLE FIRST LANGUAGE…

a handicapped person is …

a person with a disability

a mentally retarded person is …

a person with an intellectual disability/developmental disability

an autistic boy is …

a boy with autism

a handicapped parking space is …

an accessible parking space

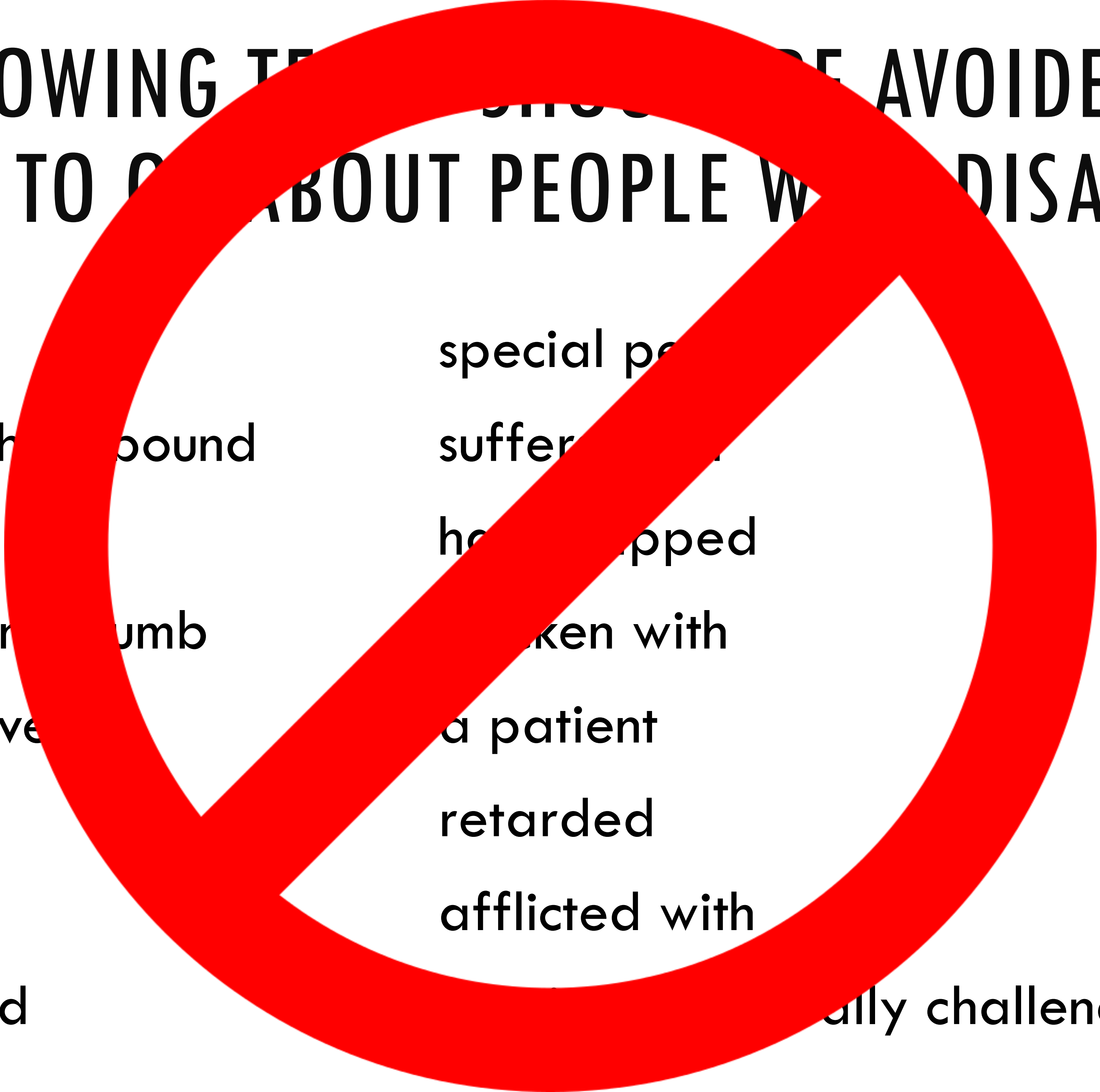
AVOID EUPHEMISMS

Such as

“physically challenged”
“special needs”
“differently abled”
“handicapable”

Many disability groups object to these phrases because they are considered condescending and reinforce the idea that disabilities cannot be spoken of in an upfront and direct manner.

THE FOLLOWING TE SHOU E AVOIDED WHEN SPEAKING TO O ABOUT PEOPLE W DISABILITIES:



- invalid
- wheelch bound
- mongol
- deaf ar umb
- defective
- mute
- victim
- crippled
- special pe
- suffer
- h pped
- ken with
- a patient
- retarded
- afflicted with
- lly challenged

GENERAL GUIDELINES FOR TALKING ABOUT DISABILITY:

Do not refer to a person’s disability unless it is relevant to the conversation.

When referring to a person’s disability, use "People First Language."

Avoid referring to people with disabilities as "the disabled,” “the blind,” “the epileptics,” “the retarded." Descriptive terms should be used as adjectives, not as nouns.

Use the word "disability" rather than "handicap" to refer to a person’s disability. Never use "cripple/crippled" in any reference to a disability.

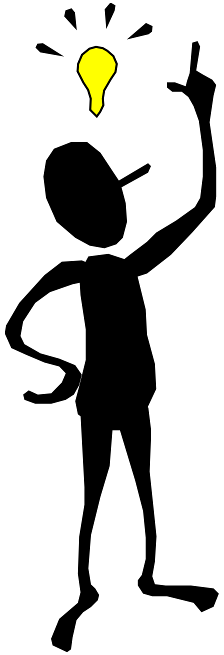
West Virginia Developmental Disabilities Council
http://www.wvddc.org/people_first.html

GENERAL GUIDELINES FOR TALKING ABOUT DISABILITY:

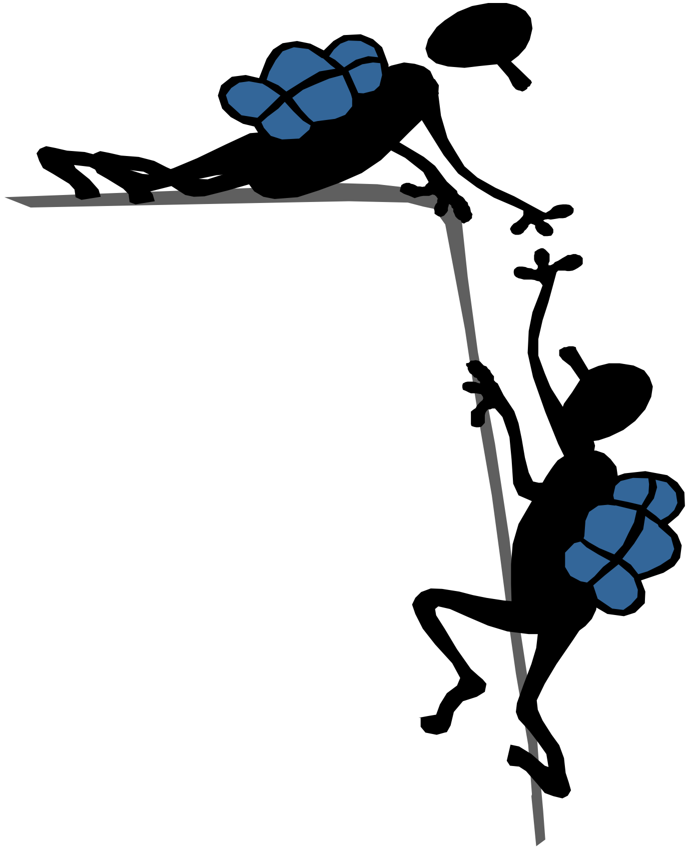
Avoid negative or sensational descriptions of a person’s disability. Don’t say "suffers from,” “a victim of,” or “afflicted with." These portrayals elicit unwanted sympathy, or worse, pity toward individuals with disabilities. Respect and acceptance is what people with disabilities prefer.

Don’t use "normal" or "able-bodied" to describe people who do not have disabilities. It is better to say "people without disabilities," if necessary to make comparisons.

West Virginia Developmental Disabilities Council
http://www.wvddc.org/people_first.html



Challenges & Strengths of Families



"If I seem overly involved in my child's life, overprotective, controlling…(fill in the blank) … please understand that it is exactly this quality that has made it possible for me to help my child to survive and to get as far as he has in school and in life."

Parent & FAN Team Representative, **FAN Team**
(Hays CISD's **F**amily **A**dvocacy **N**etwork) November 14, 2005

Raising a child with a disability poses a number of challenges for a family

adapted from: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES NEED TO BECOME BICULTURAL AND MUST LEARN A NEW LANGUAGE

They are members of both the typical culture and the culture of disability. In order to communicate effectively with service providers, families must learn medical terminology and professional jargon.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FREQUENTLY USED EDUCATION ACRONYMS/TERMS IN SPECIAL EDUCATION

1. ADD
2. ADHD
3. AODA
4. APR
5. ARRA
6. AT
7. AYP
8. BIP
9. CASS
10. CCDEB
11. CD
12. CIFMS
13. CEC
14. CEIS
15. CESA
16. CFR
17. CREATE
18. CSHCN
19. CSPD
20. DCS
21. DCTF
22. DD Council
23. DHFS
24. DLSEA
25. DOC
26. DPI
27. DVR
28. EBD
29. EC
30. EDGAR
31. EOCA
32. ESY
33. FACETS
34. FAPE
35. FBA
36. FERPA
37. GLARRC
38. GPR
39. IDEA
40. IEP
41. LEA
42. LPP
43. LEP
44. LRE
45. NCLB
46. NCRRC
47. OCR
48. OHI
49. OI
50. OSEP
51. OSERS
52. OT
53. PPS
54. PT
55. PLOEP
56. RCC
57. REACh
58. READS
59. RSN
60. RtI
61. SAP
62. SBS
63. SDD
64. SEA
65. SEP
66. SIP
67. SPDG
68. SLD
69. SPP
70. TBI

FAMILIES ARE RESPONSIBLE FOR ORGANIZING AND COORDINATING CARE FOR THEIR CHILD

They often monitor multiple service providers and a vast array of community and/or financial resources in addition to completing all of the activities of daily living and work.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES PROVIDE THE BACKUP FOR SERVICE PROVIDERS AND RESOURCES

They are often called upon to provide primary medical or behavioral care for their child, or to access a particular resource, and to be flexible enough to accommodate emergency situations.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES INCUR ADDITIONAL FINANCIAL RESPONSIBILITIES IN ORDER TO PROVIDE FOR THEIR CHILD

At a time when many families must stay at home to care for their child with a disability, they often incur additional out-of-pocket expenses. Some adaptive equipment and medications are not covered by any insurance or program.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

RAISING A CHILD WITH A DISABILITY OFTEN BRINGS OUT OR DEVELOPS A NUMBER OF STRENGTHS IN FAMILIES.

adapted from: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES DEVELOP SKILLS TO SUCCESSFULLY COORDINATE OR PROVIDE THEIR CHILD'S CARE

They learn that they have the ability to organize resources and supports and to provide technical care for their child.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES EFFECTIVELY ADVOCATE ON BEHALF OF THEIR CHILD

They can receive personal satisfaction from helping to ensure that their child's needs are met. They can also use these persuasive skills in other areas of their life.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES LEARN TO MEET THEIR OWN NEEDS AND MAINTAIN A HOPEFUL ATTITUDE

This may involve developing new relationships and taking risks. Support systems that include other families with members who have a disability are cited by families as the most helpful.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

FAMILIES LEARN TO THINK CREATIVELY IN ORDER TO MAINTAIN BALANCE OR HOMEOSTASIS IN THEIR LIVES

Adjusting to a new family member requires some changes within the family. This is heightened by all of the needs that must be met when an individual with disabilities becomes part of a family.

From: *No Place Like Home*, Family Support Planning for Children with Developmental Disabilities Training Curriculum, Karol Wasserman, Spaulding for Children, 1997

SO, WHAT ISSUES ARE PARENTS ENCOUNTERING AT THE DIFFERENT LIFE CYCLE STAGES OF THEIR CHILDREN WITH DISABILITIES?

WHAT ARE THEY THINKING ABOUT?

WHAT *ARE* THEY DOING?

WHY, OH WHY, ARE THEY DOING IT *THAT* WAY?

Possible Issues Encountered at Life Cycles

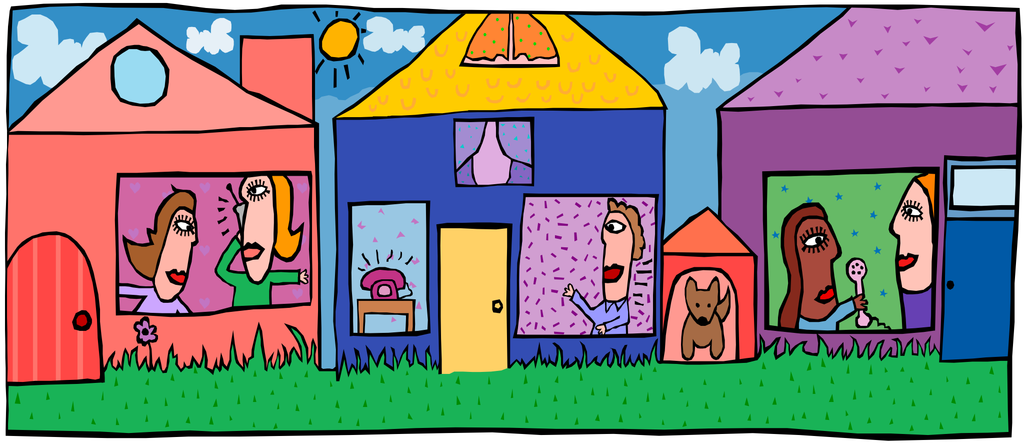
WHAT PARENTS WANT …

In a survey asking parents what they would like to see for their child at the age of 21, 75% agreed they want their children

- to be happy and to have friends,
- to be part of a neighborhood that welcomes them, and
- to make a contribution to society.

Source: Lisbeth Vincent, PhD, National Parent to Parent Conference, Tampa, Fl., 1990

Community Resources



Resources We Think You Should Know About

- ✓ Education Service Centers
- ✓Partners Resource Network
- ✓Partners in Policymaking

✓Statewide Resources

✓Statewide NICU Resources

Texas Parent to Parent

NOTHING ABOUT ME WITHOUT ME

- https://www.navigatelifetexas.org/en/videos/video/nothing-about-me-without-me

Why we do it!!!!

Texas Parent to Parent

www.txp2p.org; http://www.txp2p.org/resources/

Navigate Life Texas

www.navigatelifetexas.org;
https://www.navigatelifetexas.org/en/services-groups-events

Parent Companion

www.parentcompanion.org
http://www.parentcompanion.org/article/finding_services_and_resources_in_texas/First%20Step

Parent to Parent USA

www.p2pusa.org

Texas Parent to Parent

www.txp2p.org

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