## Welcome!!!!!



# Care for the Care Giver

### 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 and many volunteers (need MORE!)
- Many years of experience providing parent to parent support
- Statewide nonprofit (§501 (c)(3)) headquartered in Austin



### What We Do

- Match parents (if requested) emotional support or information about resources, etc.
- Provide trainings (ex: advocacy, Medicaid waiver programs, self-determination, people first language, etc.)
- Annual conferences (Statewide and 3 regional)
- Resource Directory
- Quarterly Newsletters
- List Serv for parents and family members (regional areas and issue/disability specific)



### **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





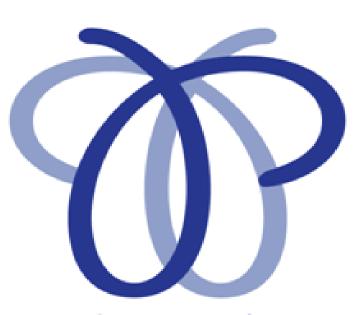
- decrease stress and isolation
- help families find or create resources for support
- provide technical support to families or parent groups





















### A caregiver is...

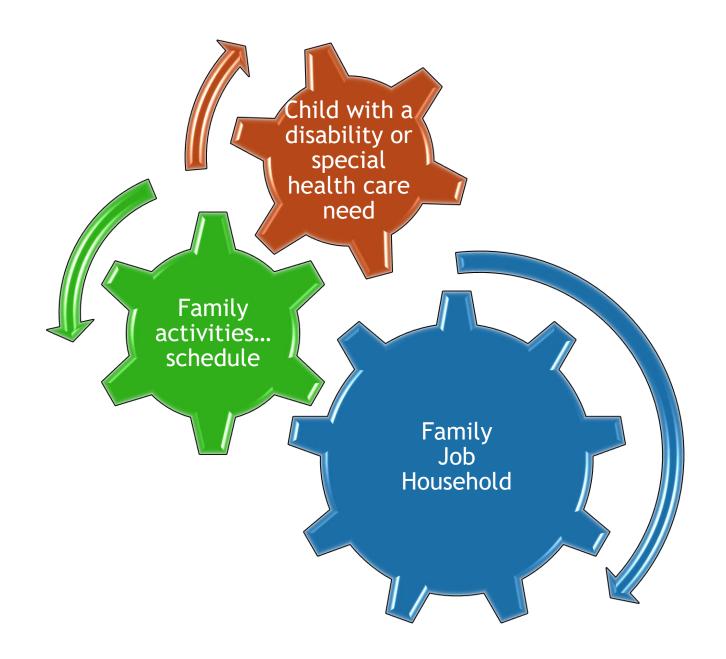
anyone who provides help to another person in need, such as a spouse/partner who is ill, a child with a disability, or a parent who is aging.

However, people who care for a family member often do not identify themselves as a "caregiver."

### Caring for yourself

one of the most important one of the most often forgotten

things you can do as a caregiver.



### Reducing personal stress...



# Taking care of yourself



### Signs of stress

- Bodily reactions: fatigue, physical aches and pains, loss of appetite, lack of sexual interest
- Sleep problems
- Sadness, resentment, depression
- Anger and irritability

### Reprioritize

- Set realistic goals
- Focus on what you are able to provide
- Say "No"



### Organize

- Break it down into manageable steps
- Make lists
- Establish routines



### Accept Help





Be prepared with a list of how others can help and let the helper choose what they would like to do.







### Preserve Self Essence







### Fill your bucket...



- Take a break without feeling guilty
- Get connected to other parents
- Spend time with non-judgmental friends/family
- Set personal health goals
  - Check ups
  - Exercise goals

# Bill of Rights of Parents Of Children with Disabilities

Parents are acutely aware of their responsibilities to provide for their offspring.

However, as parents of a child with a disability, we often get caught up in managing the details and forget that the rights we have are the same rights everyone else enjoys.

### **FREEDOM TO:**

- Feel that you have done the best you can.
- Enjoy life as intensely as possible, even though you have a child with a disability
- Let your child with a disability have his/her own privacy.
- Have hostile thoughts occasionally without feeling guilty.
- Enjoy being alone at times.
- Have a vacation yearly without the children; couples have dates, celebrations, weekends away, time together to enhance your relationship.
- Say at times that you do not want to talk about your problems.
   Say, "I'm tired of talking about my child with a disability."
- Fib occasionally and say everything is fine. Do not feel compelled to tell the truth to everyone who asks.
- Tell your child if you do not like certain things she/he does, even though she/he has a disability.

### **FREEDOM TO:**

- To not praise your child gratuitously because you have been told to offer much praise.
- Freedom to devote as much time as you want to the cause of disabilities, and then get away for a while, and return if you want.
- Tell teachers and other professionals what you really feel about the job they are doing; demand they respect your opinions.
- Tell people about your child's progress and achievements with a real sense of pride.
- Have your own hobbies and interests.
   Spend a little extra money on yourself even though you feel you cannot afford it.



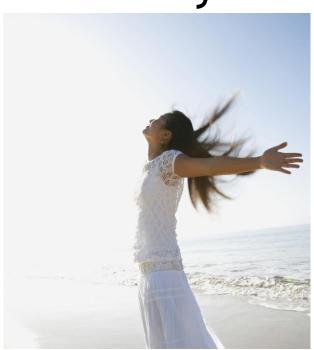
### WARNING:

Parents who do not enjoy all of these freedoms are in trouble.

Martyred parents are seldom appreciated by anybody, even their children.

# Choose today to do it for yourself.

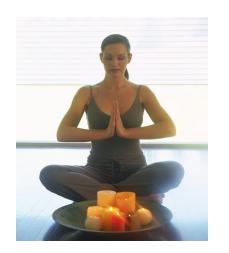
Just five minutes to start and the future looks brighter already!



















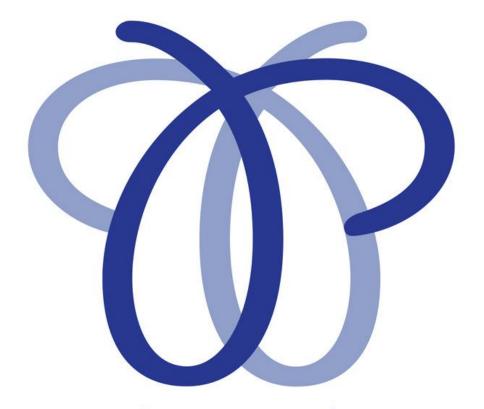


### Different Disabilities, Similar Paths



Our children may have different disabilities but we often travel very similar paths.





### Texas Parent to Parent

1805 Rutherford Lane, Suite 201 Austin, Tx. 78754 866-896-6001 www.txp2p.org

Martha C. Aguilar Martha. Aguilar@txp2p.org