

Impact of a Child with Disabilities on a Family

Texas Aging and Disability Resource Centers Training
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Goals of this Presentation

- Give you a glimpse of challenges faced by families who have children with disabilities (understanding that there are numerous blessings as well!)
- Gain sensitivity to the needs of many of these families
- Strategies to provide effective assistance

Grieving Process Experienced by Parents of Children with Disabilities:

Shock

Denial, Unrealistic Hope

Fear

Anger

Bargaining

Guilt

Sorrow and Depression

Acceptance

Understanding





Sibling Concerns

Financial Constraints

Cost of 1 month supply:
Pediasure formula - \$330
Feeding bags - \$150

Cost of custom manual
wheelchair –
\$6,000 - \$15,000



School Roadblocks and Frustrations

Difficulty Finding and Keeping Good Child Care



Sleep Deprivation



Marriage Difficulties

No time for each other

Grieving at different times in different ways

Dads typically have harder time handling diagnosis



Demands from Professionals

(Doctors, therapists, teachers, social workers, etc.)



Nursing Care



Guilt

Fears

Isolation

**Never ending
responsibilities
night or day**



Ways You Can Make a Difference

Strategies for ADRC's to Provide Effective Assistance



1. Listen with willingness to dig deep to gain a better understanding of what is really needed.

2. Problem solve.

3. Instead of just giving a referral, call resource ahead to make sure this is the right place/person to help individual.

4. Call back to let them know the correct resource information so they aren't passed around and around.

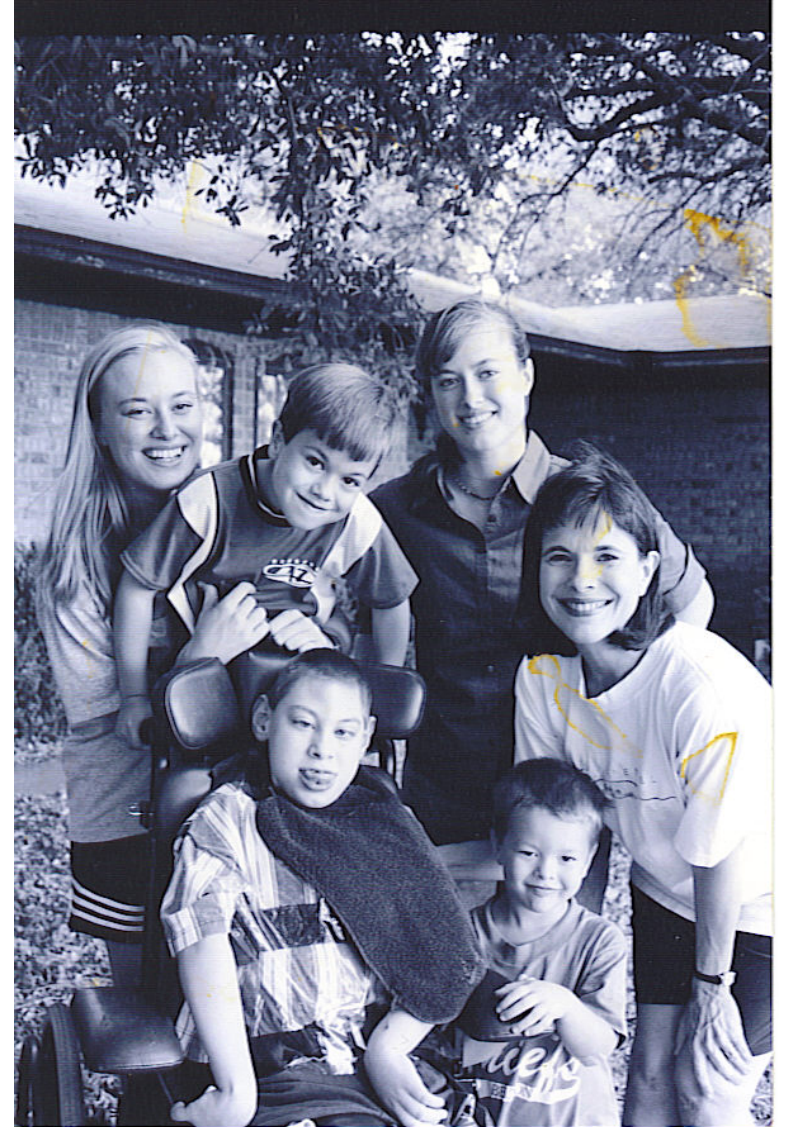
5. Follow up to find out if resource was helpful.



6. Avoid being judgmental and taking the role of gatekeeper of resources.

—Understand that some of the barriers aren't willful. (Appointments missed can be due to life issues rather than just being belligerent.)

—Don't make judgments regarding what a person needs (iPad for communication, alternative pain management help such as massage). Families are often denied resources by the very people who are in place to help.



7. Have a working knowledge of resources, such as Medicaid and special education;

AND/OR

8. Know who the experts are who have this information in your community. Develop relationships with the experts in your community.



Examples of Statewide Community Experts in Children's Resources:

Children with Special Health Care Needs Contractors:

<https://www.dshs.state.tx.us/cshcn/community-based-contractors.shtm>

Texas Parent to Parent:

www.txp2p.org





9. Human answer the phone and not just web-based information.

10. If a phone message must be left, put a warm message –“We want to hear from you.” “We will call you back.”

11. Admit when you don't know the answers to callers' questions. Tell them you will do your best to find resources to help.

12. Avoid using acronyms. Use common everyday terminology.

13. Educate the local medical community to look for and be sensitive to respite needs of caregivers. Provide them with respite resource information.



Questions

