

CHALLENGES FACING PARENTS WITH DEVELOPMENTAL DISABILITIES

Life experiences of parents with developmental disabilities may take their toll over time, especially if others have negatively valued the parents. Over time, parents may have internalized these negative expectations. Parents with developmental disabilities may report:

Socialization Experiences

- learned dependency
- rewarded for obedience
- not trained for self-sufficiency
- loyal to kin
- learned not to question authority
- learned to fear authority figures
- lack normal problem-solving skills
- limited social skills
- expect social relationships to be "unequal"
- rely on a "benefactor" to make decisions
- felt stigmatized and unwanted
- learned to use cover-up techniques and compensatory behavior to conceal deficits
- experienced harsh consequences for not meeting unreasonable expectations

Life Experiences

- deprivation and neglect
- abuse and trauma
- poverty, unemployment and lack of job skills
- mistreatment at the hand of "helpers"
- overwhelming circumstances

Learning Style Differences

- learning deficits such as processing or memory problems
- limited functional academics such as reading or writing
- limited ability to use problem-solving in complex or unfamiliar situations
- difficulty keeping track of time
- difficulty applying knowledge from one situation to another
- difficulty discriminating

Which May Have Resulted In

- low self-esteem
- shut down out of fear
- confusion and panic
- inability to cope and comply
- lack of trust
- self-protective defenses

CRITICAL ELEMENTS OF INTERVENTION

ESTABLISHING A RELATIONSHIP

The caseworker must patiently establish a positive, trusting relationship. Past experiences may have left the parent very distrustful of authority figures. Parents may initially feel quite intimidated and fearful. They may even deny or minimize the difficulties in an attempt to please the caseworker. Caseworkers should remember:

- don't make assumptions based on the initial contact
- take time to establish rapport
- understand that there may be a period of testing, i.e., missed appointments, unwilling to answer the door or participate in conversations
- convey genuine interest, respect, honesty, consistency and model good boundaries
- avoid criticism, advice-giving such as "you should..., you need to..."
- validate feelings, offer choices, explain consequences
- use humor often and appropriately

Caseworkers must pay attention to the basic survival needs of the family. The parent may be preoccupied with survival issues, including a sense of security and belonging. These issues must be addressed first or they will distract from the focus on parenting issues. The caseworker may provide referrals to appropriate community agencies. They should assist with the applications. The parent may need help and may be too embarrassed to ask for help.

SETTING REALISTIC, REASONABLE, AND FAIR GOALS

Make sure the expectations of the treatment plan goals are:

- 1. Realistic**
- 2. Reasonable**
- 3. Fair**

EACH PARENT'S LEARNING STYLE NEEDS TO BE CONSIDERED!

1. Realistic

Remember the special education model. Children with learning problems are not expected to learn to read at grade level after a six-week crash course in reading. Special education stresses individual learning goals that reflect sequential steps that are paced over time.

Make sure the expectations are **realistic!** For example:

- Does the parent have transportation?
- Does he/she know how to use public transportation?
- Does he/she know how to get to the referral agency?
- Could he/she be taught to use public transportation?
- By whom?
- What learning strategy would be most effective?

**THERE IS NO CRASH COURSE
IN PARENTING FOR THIS POPULATION.
METHODS AND MATERIALS MUST BE
APPROPRIATE AND PROVIDED BY
TRAINED PROFESSIONALS.**

2. Reasonable

Make sure the expectations are **reasonable**. Explicit, intensive-training methods should be geared to individual needs! Beginning strategies could include:

- select (with the parent) a few high priority learning tasks
- focus on one task at a time
- break the task down into its simplest steps
- teach in the context of actual life situations
- model and demonstrate
- use repetition
- use concrete examples
- use guided practice
- use corrective behavior and positive reinforcement
- allow the parent to set the pace
- extend the time frame beyond the "typical"
- watch for signs of fatigue and disinterest

3. Fair

Make sure the expectations and the process is **fair**. After all, what is success?

Success is giving the parent a fair chance to make necessary changes, whether this results in out-of-home placement or the child remaining at home.

SOME QUESTIONS TO THINK ABOUT

1. Do you look beyond the diagnosis and the stereotype?
2. Have you put yourself in the parent's situation? How would you feel as a person with a developmental disability?
3. Do you communicate that you respect the parent as a person of value?
4. Do you really believe this parent is your equal and has knowledge and expertise about his or her own child?
5. Do you listen to the parent and avoid using jargon and technical terminology?
6. Do you value and respect the parent's time as much as your own by keeping appointments and returning phone calls in a timely manner?
7. Do you follow through on your commitments to the family, modeling consistency and dependability?
8. Do you suspend judgment in conversation with the parent, avoiding critical or shaming remarks?
9. Do you make every effort to steer families toward solutions and resources and give the parent a fair chance to success?
10. Do you obtain information from other service providers that will help identify the needs of the family and the appropriate strategies for intervention?
11. Do you have sufficient knowledge of parents with developmental disabilities to ethically treat or provide services to this family?