

Working with parents who have developmental delays.

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What is a developmental disability?

- An IQ of less than 70 (75 in some instances)
- Difficulties or delays in learning, social skills, everyday functioning (ADL's or IADL's which include housekeeping, budgeting, grooming and hygiene, medication management, laundry, toileting, getting from place to place, use of telephone and level of supervision needed in order to be safe)
- Age of onset must be before 21

What are the levels of disability?

Mild: 50-69

Moderate: 35-49

Severe: 20-34

Profound: below 20

Historical points of interest regarding people with disabilities

- How people with disabilities are treated is dependent on the customs and beliefs of the time they live in.
- Society has gone from no tolerance and brutal treatment to the idea of equal rights for people with developmental disabilities.

Sterilization

- The belief from the early 1900's was that people with MR and disabilities could not raise their own children and should not have the opportunity to become pregnant. This led to sterilization.
- From 1907 onwards, 60,000 people who were described as insane, idiotic, imbecile, feeble-minded or epileptic were forcibly sterilized, often not being told what was being done to them.
- 1971-the Declaration on the Rights of Mentally Retarded Persons guarantees that mentally retarded people have the same rights as anyone else. Whether this includes the right to having and parenting children is still a debate today.
- The forced sterilization laws were finally revoked in the 1980's.

The stigma of a family with a parent who has a developmental disability.

1. Other family members will end up raising the children, whether they want to or not.
2. Concerns for the physical and emotional well-being of the child.
3. The parents' needs for public assistance.
4. The parent will neglect or abuse the child.
5. The child will be disabled.

IQ is not a predictor of how well a person can parent their child.

“Normal” parents have the same issues too!

Why are we seeing more parents with DD?

- Increased recognition of the rights of people with DD.
- The end of forced sterilization.
- We do not teach them about sexuality and prevention of unwanted pregnancy!!!!!!
- Increased movement of people with DD into communities and out of state centers.
- People with disabilities are raised at home by their families instead of being institutionalized.

Problems with the “system”

- Parents with DD do not have an effective “lobbying” group. Very little funding is put towards this.
- Programs that focus on parents with DD specifically are very rare.
- Parenting classes and such are geared towards “normal” parents and give very little consideration to parents who cannot learn in a traditional setting.
- The inability of parents with DD to find a living wage job, therefore having to rely on public benefits to support their family.
- Having a “head in the sand” mentality when it comes to teaching people with DD about relationships, appropriate sexual behavior and giving them an opportunity to interact with potential partners so they can develop positive relationships.

Concerns to take into account in families with a parent with DD:

- Inadequate parenting skills.
- Risks to children.
- Children parenting their parent.
- Lack of resources to support a parent with DD.
- Generational parenting behavior.
- Suspicious of working with service providers.

What can we do?

- Do not assume a parent with a disability cannot parent their children.
- Identify families with a parent with DD as early as possible.
- Educate children and adults with DD about sex, relationships and parenting from as early as possible. They are sexual beings, and just because it is ignored, does not mean that part of them will go away. Provide opportunities for them to develop relationships and social skills.
- Develop local programs that will cater to the needs of parents with DD. Make materials and services accessible to them so they can find, and get what they need.

Best practices when working with parents with DD:

- Remember that they love their children and they want to succeed just like anyone else. They deserve to love and parent their children!
- Do not assume that what you think is a problem is a problem to them.
- Unless it is a safety, abuse or neglect concern, let the parent dictate what happens to their own family. You are supporting them, not telling them how to do it the way you would.
- Spend time getting to know the family and as many people that support them as possible.
- Remember that some parents may be very suspicious of the “system”. You may have to start very slow when you start to work with them. Give it time for the relationship to build. They have to trust you because you could be involved in some very private details of their life.
- Never belittle or talk down to a parent.
- Services need to be tailored to the family.

- Provide services in the natural environment to help foster learning and generalization.
- BE FLEXIBLE!!!
- Don't focus on the disability, focus on the person.

Teaching Methods:

Traditional methods (sitting in a classroom, giving handouts, etc.) do not always work. Unfortunately, there are few curricula available for teaching families with a parent who has DD.

Here are some ideas:

- REPETITION, REPETITION, REPETITION!! Once is NOT enough!!
- Role playing
- Hand over hand
- Visual cues
- Adapting the Environment
- Lists
- Modeling
- Follow up on any visit to make sure the parent understood you and to go over the skill again. Help them understand.
- Be very concrete. Don't rely on abstract thoughts or explanations. Be able to show what you mean.
- Use teachable moments.
- Share information in ways other than writing, if you can.
- Task Analysis-breaking a task down into smaller steps and learning one step at a time.

Once you get to know a family, you can cater your teaching style to what they respond best to. Most importantly, always let them take the lead in their family and teach them the things they can do when you are not there. The idea is to increase their independence, not their dependence on you.

What are some situations in which you may have to help?

- Finding resources and linking the family to the things they need.
- Help with making and getting to appointments. You may have to remind them that they need to make an appt. in the first place.
- Coordinating and keeping in touch with all providers in the family's life, including schools, public services, family etc...so that the parent does not get conflicting information.
- Filling out forms, applications and other benefit paperwork, especially if the parent can't read.
- Behavior management, especially if their children have a diagnosis.
- Providing opportunities for socializing with other moms.
- Transportation.
- Help with finding housing or utilities or food.
- Working with the parent's own MI issues and counseling.
- Incarceration or contact with the DOC.
- Court and child custody issues.
- Money management
- Medication management

