WORKING WITH FAMILIES WHO HAVE A CHILD OR PARENT WITH A DISABILITY

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This workshop is sponsored by the NASW Specialty Practice Sections
PRESENTATION

ASSUMPTIONS, BIASES, AND LIMITS

- All presentations and analyses is subject to bias and/or selective process.....this presentation included.
- No matter how much I think I know, someone always knows more!
- This presentation is designed to appeal to various levels of experience and expertise.
- Working successfully with families that have a member with a disability requires substantial focus on individual, family and community systems.
- This presentation was born from years of experience, all from a strength-based perspective.
- Working in this area is complicated due to the infinite number of variables related to specific disabilities, family and community preconceived thoughts about disability and the multi-variability of the individual with a disability, as he/she changes.
Age maturity and educational levels have a tremendous impact on how the family moves forward and adjusts to a member who has a disability.

Even though this presentation looks at disability types, the vast amount of understanding and eventual work is based on the individual, family, and community.

Poverty has a tremendous impact on families with a member who has a disability and poverty exacerbates all problems that families face.

We do not define the Potential of a child or a parent with a disability. We nurture their attainment of goals, assess for needed resources, and help them see new horizons.

Use of disability terms and categories is for convenience of identification only. I apologize for any generalizations that may occur. I firmly believe in the individual as the most important identifier.

The final disability is death....we cannot underestimate the effects that anticipation of death or death itself has on the family.
## Prevalence of Disability by Percentage

**Special Education vs. Other Public School Students**

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>1980-81</th>
<th>1990-91</th>
<th>2000-01</th>
<th>2006-07</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Disabilities</td>
<td>10.1</td>
<td>11.4</td>
<td>13.3</td>
<td>13.4</td>
</tr>
<tr>
<td>Specific Learning Disability</td>
<td>3.6</td>
<td>5.2</td>
<td>6.1</td>
<td>5.4</td>
</tr>
<tr>
<td>Speech/Language Disability</td>
<td>2.9</td>
<td>5.2</td>
<td>6.1</td>
<td>3.0</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>2.0</td>
<td>2.4</td>
<td>3.0</td>
<td>3.0</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>0.8</td>
<td>0.9</td>
<td>1.0</td>
<td>1.1</td>
</tr>
<tr>
<td>Hearing Impairments</td>
<td>0.2</td>
<td>0.1</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Orthopedic Health Impairments</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Other Health Impairments</td>
<td>0.2</td>
<td>0.1</td>
<td>0.6</td>
<td>1.2</td>
</tr>
<tr>
<td>Visual Impairments</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>0.2</td>
<td>0.2</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td>Autism</td>
<td>---</td>
<td>---</td>
<td>0.3</td>
<td>0.5</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>0.1</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>---</td>
<td></td>
<td>0.4</td>
<td>0.7</td>
</tr>
</tbody>
</table>
## Prevalence of Disability by Category & Age

<table>
<thead>
<tr>
<th>DISABILITY TYPE</th>
<th>NUMBER</th>
<th>PERCENT GEN. POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>5 Years and Over</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive difficulty</td>
<td>13,425,171</td>
<td>4.8</td>
</tr>
<tr>
<td>Ambulatory difficulty</td>
<td>19,189,449</td>
<td>6.9</td>
</tr>
<tr>
<td>Self-care difficulty</td>
<td>7,203,018</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>18 Years and older</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent living difficulty</td>
<td>12,915,318</td>
<td>5.7</td>
</tr>
<tr>
<td><strong>5 to 17 years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive difficulty</td>
<td>2,068,781</td>
<td>3.9</td>
</tr>
<tr>
<td>Ambulatory difficulty</td>
<td>365,131</td>
<td>0.7</td>
</tr>
<tr>
<td>Self-care difficulty</td>
<td>450,978</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>18 to 64 years</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive difficulty</td>
<td>7,695,235</td>
<td>4.1</td>
</tr>
<tr>
<td>Ambulatory difficulty</td>
<td>9,628,591</td>
<td>5.1</td>
</tr>
<tr>
<td>Self-care difficulty</td>
<td>3,332,551</td>
<td>1.8</td>
</tr>
<tr>
<td>Independent living difficulty</td>
<td>6,531,154</td>
<td>3.5</td>
</tr>
<tr>
<td><strong>65 years and older</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive difficulty</td>
<td>3,661,155</td>
<td>9.8</td>
</tr>
<tr>
<td>Ambulatory difficulty</td>
<td>9,195,727</td>
<td>24.7</td>
</tr>
<tr>
<td>Self-care difficulty</td>
<td>3,419,489</td>
<td>9.2</td>
</tr>
<tr>
<td>Independent living difficulty</td>
<td>6,384,164</td>
<td>17.2</td>
</tr>
</tbody>
</table>

Source: 2008 American Community Survey
PREVALENCE OF DISABILITY BY ADDITIONAL DEMOGRAPHICS

2000 Census:

- All US/All levels 19.3%. 9.4% Severe.

- Gender: Male 19.6%; Female 19.1.

- Race: White 18.5%; Black 24.3%; Native American 24.3%; Asian/Pacific Islander 16.6%; Hispanic 20.9%.

<table>
<thead>
<tr>
<th>AGE (YEARS)</th>
<th>% WITH DISABILITY</th>
<th>% WITH SEVERE DISABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 15</td>
<td>8.8</td>
<td>3.6</td>
</tr>
<tr>
<td>15 – 24</td>
<td>10.4</td>
<td>5.0</td>
</tr>
<tr>
<td>25 – 44</td>
<td>11.4</td>
<td>7.5</td>
</tr>
<tr>
<td>45 – 54</td>
<td>19.4</td>
<td>12.8</td>
</tr>
<tr>
<td>55 – 64</td>
<td>30.1</td>
<td>20.8</td>
</tr>
<tr>
<td>65 – 69</td>
<td>37.4</td>
<td>26.1</td>
</tr>
<tr>
<td>70 – 74</td>
<td>43.8</td>
<td>27.6</td>
</tr>
<tr>
<td>75 – 79</td>
<td>55.9</td>
<td>37.8</td>
</tr>
<tr>
<td>&gt; 80</td>
<td>71.0</td>
<td>56.2</td>
</tr>
</tbody>
</table>
Disability: Family & Children

A Review of Factors and Facts:
Quality and Quantity of Caregiving by the Family
(Research by Rupp & Ressler)

- Parental Low Education: (In practice, I have found this factor relates to higher likelihood of poverty, possible cognitive/learning deficits, or other life factors that are often associated with lower educational level for parents.)
- Disability of a Parent
- Single vs. Two Parent Families
- Severity and Nature of the Child’s Disability
- The Presence of Pre-School Age Children in the Household
- The Availability of Extended Family Caregivers.

In addition to above found by Rupp & Ressler, I have found that geographic factors; commitment of the public education system; State Medicaid waivers that extend public supported healthcare; and, economic factors of both the family and community also have effect.
A Review of Factors and Facts:
Life Expectancy & Expected Life Time Medical/Treatment Costs Selected Disabilities

<table>
<thead>
<tr>
<th>Disability</th>
<th>Life Expectancy (Years)</th>
<th>Medical And/Or Medical Support Cost Per Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without Marked Disability</td>
<td>78</td>
<td>$2,793 (&lt; 65 Years)*</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>Negligible Difference</td>
<td>$5,486**</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>60</td>
<td>$16,900**</td>
</tr>
<tr>
<td>Vision Impairment</td>
<td>52</td>
<td>$10,884**</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>Negligible Difference</td>
<td>$12,879**</td>
</tr>
<tr>
<td>Severe Autism</td>
<td>Negligible Difference</td>
<td>$41,025 ***</td>
</tr>
<tr>
<td>Cerebral Palsy (Adults)</td>
<td>30 – 70 depending on severity.</td>
<td>$30,700 – 12,118**</td>
</tr>
<tr>
<td>Serious Mental Illness</td>
<td>68</td>
<td>$16,294****</td>
</tr>
</tbody>
</table>

* U. S. Census 2000
** Center for Disease Control 2003 dollars.
HELP

WHAT MOST FAMILIES NEED FIRST

- Information
- Crisis Intervention If Necessary
- Links to Family/consumer Advocacy Organization
- Links to Family/consumer Support Organizations
- Consultation Winding Their Way Through Other Services Providers
- Potentially Free or Low Cost Legal Services Depending on Family's Ability to Pay
- Requested Clinical Assistance
Primarily interventions are from a strength based modality with an eye on change and hope.

Rehabilitation modalities often look at the identified problem in three areas: Aptitudes, Attitudes and Skills/Knowledge. Clients learn the meaning of these and how they might effect the outcome of interactions and their own perceptions of situations.

A major focus of rehabilitation is daily activities and structure. The clinician and client/parent/child makes a comprehensive list of activities, tasks and social/school/work interactions and then decide if and how the disability is impacting each one.

Daily activities/tasks are then viewed through “functional perspectives or functional aspects”. (Break down each affected activity into the required small steps to accomplish identified goals….. and what goes right and what goes wrong is determined for each.)

Concentrate on age appropriate structure. Children = play, hobbies, friends, chores & school. Adults = work, parenting/family, activities of daily living, leisure & social networks.
HELP

UNDERSTANDING INTERNAL & EXTERNAL FACTORS

- Perceived self-identity.
- Community perceptions.
- Your own hang ups and feelings.
- Influences of folks around you.
- Power, Control & Responsibility
- Concepts of independence, dependence and inter-dependence.
- Integration and community participation.
- Stigma, discrimination and persecution. Dangerous words and actions.
- Importance of work as identity.
- The Us & Them Syndrome.
Defining disability: It depends on your viewpoint!

“The only disability in life is a bad attitude.” Scott Hamilton.

“Congress acknowledges that society’s accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment.” William J. Brennan, Jr.

The term “learning disability” has appeal because it implies a specific neurological condition for which no one can be held particularly responsible and yet it escapes the stigma of mental retardation. There is no implication of neglect, emotional disturbance, or improper training or education, nor does it imply a lack of motivation on the part of the child. For these cosmetic reasons, it is a rather nice term to have around. U. S. Government Study On The Labeling of Children.
HELP

Defining disability: It depends on your viewpoint!

“Ability to live on your own terms. That’s what the disability rights movement is all about. It’s a civil rights movement. Laura Hershey Random

Some historical perceptions - a lesson in paradox.

Dis-a-bil-i-ty. n. 1. Lack of competent power, strength, or physical or mental ability; incapacity. 2. A physical or mental handicap, especially one that prevents a person from living a normal life or from performing a specific job. The Random House Dictionary. 1979.

Dis-a-bil-i-ty. n. Temporary or permanent inability to perform activities that most others can perform, usually as a result of a physical or mental condition or infirmity. The Social Work Dictionary. 1999.
Social Security Administration (SSI & SSDI). Disability under the Social Security is based on your ability to work. You will be considered disabled if you are unable to do any kind of work for which you are suited and your disability has lasted or is expected to last for at least a year or to result in death.

American with Disabilities Act (ADA): Any individual with a disability who: (1) has a physical or mental impairment that substantially limits one or more life activities; or (2) has a record of such impairment; or (3) is regarded as having such an impairment. Further, the person must be qualified for the program, service or job.

Individuals with Disabilities Education Act (IDEA): Children and youth aged 3 - 21 who are determined through an individualized evaluation and by a multi-disciplinary team (including the parent) to be eligible in one or more of 13 categories and who need special education and related services. The categories are autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, traumatic brain injury, and visual impairment including blindness. Children aged 3 through 6 (RI) experiencing developmental delays may also be eligible.
Defining disability: It depends on your viewpoint!

504 of the Rehabilitation Act of 1973 - Vocational Rehabilitation. (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such impairment, or (3) is regarded as having such an impairment. Major life activities include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. The person must be qualified for the services or job; in the case of school services, the person must be of an age when non-disabled peers who are typically served or be eligible under IDEA.

Rhode Island General Public Assistance: Adults who are 18 years old or older, have an illness, injury, or medical condition, which is expected to last at least 30 days and prevents his/her from working. (Eligibility individually determine based on evaluation. “Means test” applies.)
At Intake: Presenting problems included – Feelings of being overwhelmed, no energy, being alone, and not being able to do well in any area of life.
After 12 Sessions: Mother feeling much better, has more energy and is ready to leave therapist.
Common clinical interventions utilized with people with disabilities include: cognitive therapy and variations, insight therapy, supportive therapy, and many more. The choice, in my opinion belongs to the client or negotiated between client and therapist.

Specific therapies are used for specific mental health disorders and situations, i.e.; Autism: Applied Behavioral Analysis, Floortime, Relationship Development Intervention, The SCERTs Model (Social Communication and Emotional Regulation, Transactional Supports), Sensory Integration Therapy.

Environments may dictate use of approaches. i.e.; Public Schools: Response to Intervention (RTI), Early Intervention, Positive Behavioral Interventions and Supports (PBIS), Behavioral Intervention Plans (BIP), Comprehensive family services, Individual counseling services, Small group counseling, Social Skills Training, Brokerage Case Management, etc.

There are so many different types of therapies which are chosen based on environment, client need/preferences, and practitioner skills/orientation, it is impossible to include them all here. Each practitioner should utilize their own clinical judgment and the NASW clinical practice/ethical standards.
Clinical Considerations: Tips for the Practitioner When Working Directly with the Individual Who Has a Disability

- Do not assume help is being sought that is related to his/her disability.

- Part of the therapeutic process is determining what is and is not related to the disability. In many cases, the person is seeking assistance for the same reason others might seek assistance.

- The practitioner’s skill is needed to understand when disability is involved even when not obvious.

- Try using a task orientation to therapy. Insights often will follow. It's not about "adjustment" by the individual, it's about compensating for the impact of a disability and gaining control. In most cases, any "adjustments" are actually needed are by the community.

- Rehabilitation principles may be used in conjunction in almost any therapeutic approach.

- Regarding learning and practice of situational social skills, role play, art/theatrical approaches and milieu venues are excellent methods.
Medication: Patient Assistance Programs (PAPs) are programs set up by drug companies that offer free or low cost drugs to individuals who are unable to pay for their medication. These programs may also be called indigent drug programs, charitable drug programs or medication assistance programs. Most of the best known and most prescribed drugs can be found in these programs. All of the major drug companies have patient assistance programs, although every company has different eligibility and application requirements. (www.Rx Assist.org: Patient Assistance Program Center, 2009)

~ The ARC -http://www.thearc.org/
~ American Association of People with Disabilities -http://www.aapd.com/
~ Autism Speaks -http://www.autismspeaks.org/
~ Beach Center on Disability -http://www.beachcenter.org/
~ Brain Injury Association of America -http://www.biausa.org/
~ Depression and Bipolar Support Alliance -http://www.dbsalliance.org/
~ Easter Seals -http://www.easterseals.com/
~ Family Village: A Global Community of Disability-Related Resources -http://www.familyvillage.wisc.edu/
HELP

Resources: Local, State, & National

Who, What, When & Where

~ Institute for Family-Centered Care - http://www.familycenteredcare.org/
~ Learning Disabilities Association of America - http://www.ldanatl.org/
~ March of Dimes - http://www.marchofdimes.com/
~ Mental Health America - http://www.nmha.org/
~ Multiple Sclerosis Association of America - http://www.msassociation.org/
~ Muscular Dystrophy Association - http://www.mda.org/
~ National Alliance on Mental Illness - http://www.nami.org/
~ National Association for Down Syndrome - http://www.nads.org/
~ National Federation of Families for Children's Mental Health - http://ffcmh.org/
~ Office of Special Education and Rehabilitative Services - http://www.ed.gov/about/offices/list/osers/index.html?src=mr
~ Parents with Disabilities Online - http://www.disabledparents.net/
~ Parent to Parent USA - http://www.p2pusa.org/
~ TASH - http://www.tash.org/ (International association for people with disabilities, family members and advocate.)
POLICY IMPLICATIONS

Limited Resources and Changing Demographics

- The aging of the baby boomers will put considerable stress on the healthcare system therefore stressing service funds available to individuals with disabilities.

- Reliance on high stakes testing without alternative measures of knowledge, such as portfolios, will most likely leave some children behind who have difficulty learning to and competing in high stakes testing venues.

- Without comprehensive healthcare available to all populations, some people with disabilities will continue not to receive the best medical/mental health/substance use treatment to meet their needs.

- Supported employment options need to be expanded to include other individuals who have disabilities but cannot effectively compete without supports in our competitive employment market. Capitalism is not a social policy, it is an economic engine designed to allow businesses to compete and profit from their competition or fail. This is not generally a good environment for individuals whose needs exceed those of other workers.

- Inclusion is still the key, not just economically driven program designs.
A Little Improvement on Healthcare Access Makes a Huge Difference: Case Study
## POLICY IMPLICATIONS

A Little Improvement on Healthcare Access Makes a Huge Difference: Case Study cont.

<table>
<thead>
<tr>
<th>Factor</th>
<th>RI</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Hospital Days (per 1000)</td>
<td>297</td>
<td>356</td>
</tr>
<tr>
<td>Emergency Room Visits (per 1000)</td>
<td>577</td>
<td>590</td>
</tr>
<tr>
<td>Mental Health Utilization</td>
<td>10.3%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Substance Abuse Utilization</td>
<td>1.6%</td>
<td>.9%</td>
</tr>
<tr>
<td>Childhood Immunization</td>
<td>65.9%</td>
<td>62.8%</td>
</tr>
<tr>
<td>Adolescent Utilization</td>
<td>67.9%</td>
<td>51.8%</td>
</tr>
<tr>
<td>Follow - Up Mental Health Visit</td>
<td>64.9%</td>
<td>55.8%</td>
</tr>
<tr>
<td>Breast Cancer Screening</td>
<td>64%</td>
<td>55.8%</td>
</tr>
<tr>
<td>Prenatal Care Access</td>
<td>82.4%</td>
<td>76%</td>
</tr>
<tr>
<td>Well Child Visits (Adolescents)</td>
<td>74.1% (52.9%)</td>
<td>60.5% (37.4%)</td>
</tr>
</tbody>
</table>
QUESTIONS, ANSWERS & DISCUSSION
ADDENDUM

Relevant Social Policy Facts and History Regarding Disability

- Mutual Aide. Family/Friends/Community Members. All Cultures.
- 1349 England year of the Black Death. "Statute of Laborers". All able bodied persons were ordered to work, and giving of alms was forbidden.
- English Poor Laws of 1601: Development of concepts of Worthy and Unworthy needy.
- Dorothea Dix (mentally ill) & the Pierce Veto
- Social Darwism 1850's. Survival of the fittest.
- Veterans Act of 1866. Established services for wounded and disabled vets. Vocational Resources in RI.
- Rehabilitation services established for the Blind mid-1940's expanded to other disabilities throughout years. Birth of Services for the blind and Vocational Rehabilitation (VR).
- Medicaid and Medicare 60's & 70's.
- Rehabilitation Act of 1973 and all addmements.
ADDENDUM

Some Important Laws Relating to Education

- 1975: The EHA is amended by the Education for All Handicapped Children Act (EAHCA) which is the parent of the IDEA.
- 1986: The EAHCA is amended with the addition of the Handicapped Children's Protection Act.
- 1990: The EAHCA is amended and called the IDEA (Individuals with Disabilities Education Act), adding transition as a requirement.
- 1997 & 1999: The IDEA is amended.
- Amendments: Individuals with Disabilities Education Improvement Act of 2004.
ADDENDUM

Americans with Disabilities Act - 1990

1. Employment (Reasonable Accommodations).


3. Public Accommodations (Applies to private sector also).

4. Telecommunications (TRSs - Relay Services & TDDs - Communication Devices for Deaf).

5. Transportation (Accessible public and private transportation.)