The number of people who have Autism Spectrum Disorder (ASD) has sky-rocketed over the last two decades.

1 in 10,000 2004
1 in 68 2014

Many have the aptitude to learn...obtain a profession...enjoy a quality of life...and be of value to our society

BUT...

Our society is terribly lacking in the knowledge and understanding of what an Autism Spectrum Disorder (ASD) or other Developmental Disability (DD) is and how these conditions impact an individual in their ability to function successfully in our society.

Researchers in Developmental Disabilities (DD) have been helping all of us know what individuals with DD are able to know, learn and do and how to teach them, and those around them, not only their potential but how to help get them there.

Unless researchers ensure that what they learn makes its way to the practitioners (family and professionals) as well as to our society at large, individuals on the spectrum of autism will not benefit...and will continue to live marginal and troubled lives...along with their families!

HISTORY ON LEGAL SUPPORTS FOR INDIVIDUALS WITH DISABILITIES IN THE UNITED STATES

1800s – 1960s
Separate and unequal lives of those with developmental disabilities (Residential facilities, warehouses, etc.)
No legal protections of significance

2 Major National Events Changed This:

WORLD WARS (WWI, WWII, & Korean War)

- Fathers, husbands, brothers, neighbors and friends went to war.
- Many returned with major disabilities.
- Society wanted to help “rehabilitate them.”
- Research funding was established to find out how to teach and rehabilitate (e.g. Orientation and Mobility developed in the VA in Chicago).

CIVIL RIGHTS MOVEMENT

LAWS AND POLICIES WERE ADVOCATED FOR AND ESTABLISHED THAT...

ALL PEOPLE in the United States had a “CIVIL RIGHT” not to be discriminated against in their access and participation in:

- Housing
- Education
- Employment
- Recreation
- Transportation
- Etc.

...regardless of their Race, Sex, Religion, DISABILITY, etc.

1970s -1990s

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>1973</td>
<td>Section 504 of the Vocational Rehabilitation Act (a civil rights law)</td>
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<tr>
<td>1975</td>
<td>Public Law 94-142 (Education of All Handicapped Children Act)</td>
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<td>1975</td>
<td>Now the individuals with Disability Education Act (IDEA)</td>
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<td>Amended in 2004 and 2007</td>
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<td>1990</td>
<td>Americans with Disabilities Act (ADA) (a broader civil rights law)</td>
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<td>Amended in 2010</td>
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HOW DO THESE LAWS WORK?

Section 504 and the ADA are closely linked. Section 504 applies to government agencies and federally-funded organizations, including schools.

The ADA applies to private as well as governmental entities, with some restrictions.

Title I of the ADA applies to employment (employers with <50 employees)

Title II of the ADA applies to government agencies

Title III of the ADA applies to public accommodations.

The ADA also protects anyone who advocates on behalf of an individual with a disability from retaliation.

HOW DO THESE LAWS WORK? (continued)

Both the ADA and Section 504 prohibit discrimination, ensure full access to services and facilities, and provide for reasonable accommodations that will enable access and inclusion.

Both utilize the same definitions of who is a qualified individual with a disability who is protected under the law.

WHO IS A QUALIFIED INDIVIDUAL WITH A DISABILITY UNDER THE ADA AND SECTION 504?

Someone who has a health condition that substantially limits a major life activity.

Major life activities include communicating, learning, interacting with others, remembering, and other things that we all do in everyday life.

Substantial limitations are required, not just minor impairments.

WHO IS A QUALIFIED INDIVIDUAL WITH A DISABILITY UNDER THE ADA AND SECTION 504? (continued)

In determining eligibility, adaptations that the person uses to improve the condition—such as medication, extra tutoring, or personal assistive technology—may not be held against the person.

The person must otherwise qualify for the activity they wish to participate in. For instance, in an employment setting, the person must have the requisite training and experience and be able to perform the primary job functions, with reasonable accommodations.

Not every person with a medical or health condition qualifies for coverage.

INDIVIDUALS WITH DISABILITIES IN EDUCATION ACT (IDEA)

The IDEA differs from Section 504 and the ADA in many ways.

The IDEA only covers public schools serving prekindergarten through high school.

To qualify for coverage, the person must be birth through age 22, must have a need for special education services/modified instruction, and must have a qualifying disability under the following categories:

Autism
Developmental Delay
Other Health Impaired
Intellectual Disability
Emotional Disability
Deafness/Hearing Impairment
Multiple Disabilities

If only accommodations, and not special education services or modification of instruction, are needed, then a student does not qualify for coverage under the IDEA. Instead a 504 plan is created.

Students can get related services under 504 plans. 
THESE DIFFERENCES ARE IMPORTANT FOR PROFESSIONALS IN THE FIELD

A diagnosis of Autism made by a doctor may not automatically qualify an individual for coverage under the ADA, Section 504 or the IDEA. Likewise, qualification under the ADA/Section 504 may not qualify a student for coverage under the IDEA. (And, similarly, the definitions and eligibility differ for these from those used for Social Security Insurance/Social Security Disability services.)

When writing reports and preparing evaluations, practitioners should become familiar with the requirements and terminology used for the specific setting for which it is needed.

Forms submitted by schools, employers and other entities need to be filled out with care. One inconsistent answer could block a patient from receiving something they need.

EDUCATION

WHAT are the ETIOLOGIES (causes) of the underlying disabilities children have?

WHAT research-based INTERVENTIONS actually work to address the
Communication
Language
Behavior
Learning
Social/Emotional
needs of the students.

WHAT developmental services ARE CRITICALLY NECESSARY for educators to address in their work educating students with developmental disabilities

Mental Health Counseling as a necessary service
Behavioral interventions such as “Applied Behavior Analysis (ABA)”
Family supports and training

IN THE EDUCATIONAL SETTING, HOW CAN PROFESSIONALS HELP ENSURE THAT STUDENTS WITH DEVELOPMENTAL AND MENTAL HEALTH DISABILITIES GET WHAT THEY NEED?

Educate families and self-advocates about the student’s condition(s) so they can advocate more effectively.

Write reports and letters explaining the student’s strengths and needs and making clear recommendations about interventions that will help them reach their potential.

Participate as a member of the IEP or 504 team.

Help educate the school about the student and his/her needs through staff trainings.

CAUTIONARY NOTE: Schools may sometimes try to communicate directly to professionals and misinterpret what is shared. Work out a plan with the student and family regarding school-practitioner communication.

ANATOMY OF AN INDIVIDUALIZED EDUCATION PLAN (IEP)

Eligibilities and Background Information
Present Levels of Performance
Goals and Objectives
Special Education Services
Related Services
Accommodations
ESY
Transition
Training for Staff

OBTAINING ELIGIBILITY FOR STUDENTS WITH INVISIBLE DISABILITIES

These include Asperger’s, ADHD, and many Mental Health Conditions (Anxiety, ODD, GAD, etc.)

Students with invisible disabilities are often denied services because their grades and test scores are on grade level; they are perceived as lazy, unmotivated, or unwilling to do what is expected of them; they are quiet and not causing a disruption in class; or they (and their families) are putting in an extraordinary effort at home to make up for their disability.

The law says that these students— if they have an impairment that affects their learning, behavior, social adjustment, emotional well-being, or independent functioning—should be eligible for an IEP.

Professionals can help pinpoint their needs and make recommendations for addressing them so that the school recognizes them.
MENTAL HEALTH COUNSELING

WHY SHOULD and HOW CAN disabled INDIVIDUALS, their FAMILIES, EDUCATORS, REHABILITATION SPECIALISTS and OTHER PROFESSIONALS address the underlying mental health needs that co-morbidly exist within the developmentally disabled population?

What kind of therapies actually WORK in improving the overall mental health of individuals with developmental disabilities?

What medical interventions (pharmacological, psychiatric, etc.) actually work in addressing qualitatively the mental health needs of individuals with developmental disabilities?

HEALTH SERVICES

What medical interventions actually work in addressing the underlying health issues of individuals with developmental disabilities?

What medical interventions do health care professionals and families need to have health insurance policies cover?

Medical interventions (pharmacological/surgical) that work and can critically impact the comprehensive health care of the individuals with developmental disabilities (ASD, Down syndrome, seizure disorders, cerebral palsy)

Mental Health Counseling/Therapy

Other interventions (language therapy, occupational therapy, physical therapy)

MENTAL HEALTH COUNSELING (Con't)

HOW CAN PROFESSIONALS HELP INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES ACCESS THESE SERVICES?

Once again, providing expertise and tailoring specifically to the agency's requirements can help tremendously.

Public school districts can provide or pay for services that are educationally-related or that help students access the schools' curriculum and services.

Medicare/Medicaid/Medwaiver

Community agencies can also provide the services, for instance Boys Town.

TRANSITION

Social skills training

Executive functioning coaching

The “soft skills” critical for the success of individuals with DD in an employment (work) situation.

Temple Grandin's faux pas

Perseverative behavior of ASD individuals (fascination vs. stalking)

Safety vs. fear with individuals with DD in work, specialized training, community interactions, etc.

Role of educators….policies critically necessary….parental advocacy, etc.

SELF ADVOCACY

How do we TEACH individuals with developmental disabilities that:

- They have a right to access major things such as employment, housing, education and more
- Appropriate strategies for communication with others “appropriately” regarding things that they need to do.
- They can ask for things important to them.
- How to ask for things important to them.
- Why they should advocate for what is important to them.

SELF ADVOCACY (Con't)

HOW family members, teachers and other service providers can TEACH individuals with developmental disabilities WHAT they need to know and be able to do if they are to TRANSITION into post high school education (college or vocational/technical schools).

WHAT they need to teach these individuals.

Why they need to teach this.

Probability the Teaching will be successful and “what it will take!”
HOW CAN RESEARCHERS HELP TURN THEIR RESEARCH INTO PRACTICE?

1. Not only write for research journals what their research has documented but go the next step and write an article in lay English at a level most families would understand outlining WHAT their research has documented/proven and WHY it is important that educators or family members know about it and be able to use it.

2. Provide the results of their research to parent organizations, other researchers, educators, health care providers, insurance companies AND local/state/federal policy makers.

3. Work with self-advocates to guide research that will address their actual needs and improve their lives.

Example organizations for researchers to submit their research findings to:

- **National Association on Developmental Disabilities**
  132 Fair Street
  Kingston, NY 12401
  800-331-5364
  info@thenadd.org

- **The Council for Exceptional Children**
  2900 Crystal Drive, Suite 1000
  Arlington, VA 22202-3517
  888-233-7733 TTY: 866-915-5000

- **Autism Speaks**
  1 East 33rd Street
  4th Floor
  New York, NY 10016
  Phone: (212) 233-6000 Fax: (212) 233-6070
  familieservices@autismspeaks.org

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