Professional Cultural Competency
while working with the Autism Community

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Three Objectives Today

Upon completion of *Professional Cultural Competency while working with the Autism Community* participants will:

1. Gain an understanding of the unique challenges and difficulties people with autism and their families face and how professionals can assist them in overcoming these barriers in a culturally sensitive manner.

Continued Objectives

2. Learn the various systems people with autism and their families navigate to gain support, treatments, and obtain services.

3. Achieve a better understanding of the additional skills needed to work effectively with individuals with autism and their families and how personal biases, expectations and limited understanding of individuals' needs can hinder effective treatment.

Definition of Culture

- The integrated pattern of human knowledge, belief, and behavior that depends upon the capacity for learning and transmitting knowledge to succeeding generations

- The customary beliefs, social forms, and material traits of a racial, religious, or social group; *also* : the characteristic features of everyday existence (as diversions or a way of life} shared by people in a place or time

- The set of shared attitudes, values, goals, and practices that characterizes an institution or organization. The set of values, conventions, or social practices associated with a particular field, activity, or societal characteristic

Defining the Culture of the Autism Community

Autistic culture is based on a belief that autism is a unique way of being and not a disorder to be cured.

Harmon A

(2004-12-20). "How about not 'curing' us, some autistics are pleading". *New York Times*. http://www.nytimes.com/2004/12/20/health/20autism.html. Retrieved 2007-11-07

The beliefs, norms, values and shared experiences and struggles, etc...of individuals with an Autism Spectrum Disorder (ASD) as well as the systems with which these families and/or individuals interact.

Social and economic systems wherein the Autism Community get their social, behavioral, emotional, and financial needs met.

The Culture of Autism
Video from ASA's 40th Anniversary

- http://www.bing.com/videos/watch/video/the-culture-of-autism/efb2ece715b56a8c12ffefb2ece715b56a8c12ff-545490731739?q=autism+culture+videos+youtube&FROM=LKVR5&GT1=LKVR5&FORM=LKVR

- The Culture of Autism video was created for the Autism Society's 40th National Conference on Autism Spectrum Disorders, July 22-25, 2009.

What is Cultural Competence?

Cultural competence implies a heightened consciousness of how clients experience their uniqueness and deal with their differences and similarities within a larger social context.
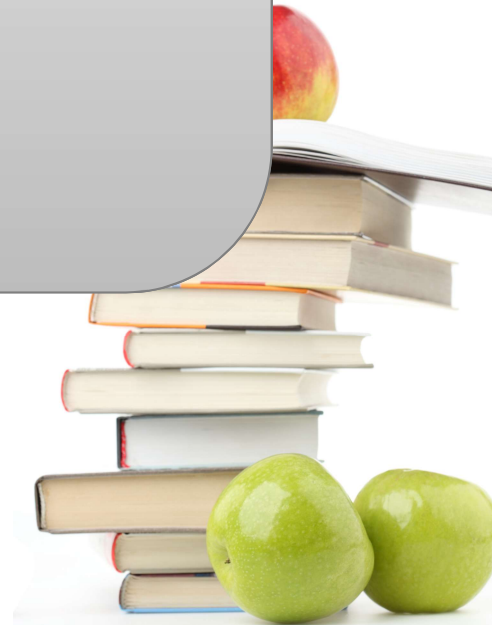
- Cultural competence is the understanding of diverse attitudes, beliefs, behaviors, practices, and communication patterns attributable to a variety of factors such as
  - Race
  - Ethnicity
  - Religion
  - Social economic status (SES)
  - Historical and social context
  - Physical or mental ability
  - Age, gender, sexual orientation
  - Generational and acculturation status

National Heart, Lung, and Blood Institute (NHLBI)
Retrieved on March 9,2011
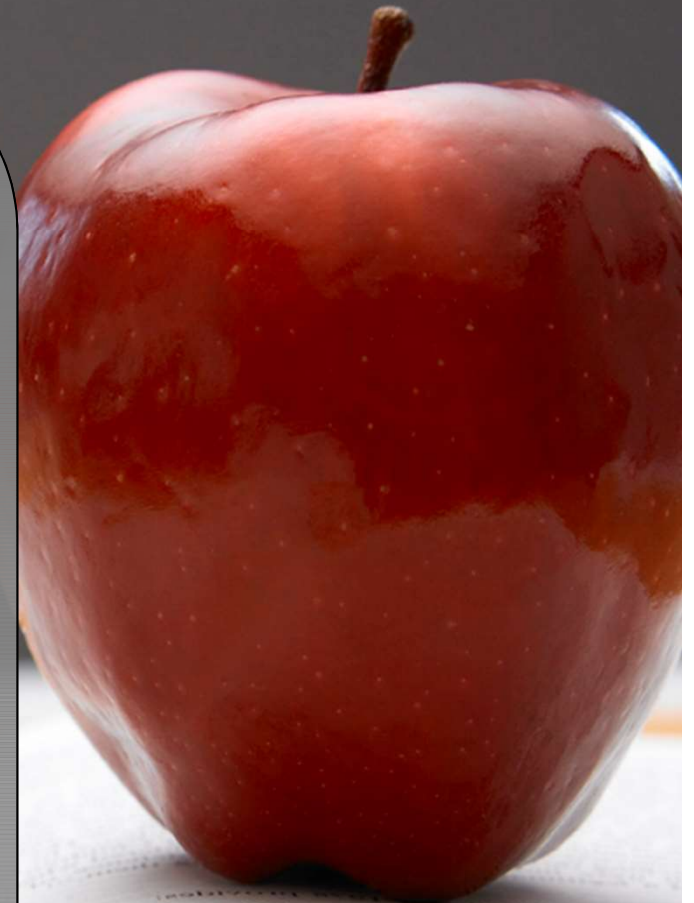
Characteristics of the Autism Community

- Language
- Challenges
- Economics
- Beliefs, stigmas, norms and subcultures
- Politics
- Provider sensitivity
- System problems
- Funding and treatment support difficulties
- Life-long disorder, grief cycles
- Like running a business full-time
- Divorce rate

Language by any other name…

Diagnosis

Identity

Terminology within the Autism Community

Aspie – a person with Asperger syndrome

Autie – a person with autism. It can be contrasted with aspie to refer to those specifically diagnosed with classic autism.

Autistics and Cousins (AC) – a cover term including aspies, auties, and their "cousins" (e.g. people with some autistic traits but no formal diagnosis)

**Curebie** – a person with the desire to cure autism. This term is highly derogatory.

Neurodiversity – tolerance of people regardless of neurological wiring

**Neurotypical (NT)** – an individual who is not on the autism spectrum

Wellness vs. Unwellness

- **Depression**
- **Chronic stress**
- **Lack of sleep**
- **Increasing debt**
- **Isolation**
- **Chronic worry and anxiety**
- **Lack of outlet**
- **Loss of personal identity**
- **Lack of support network**
- **Unresolved grief**
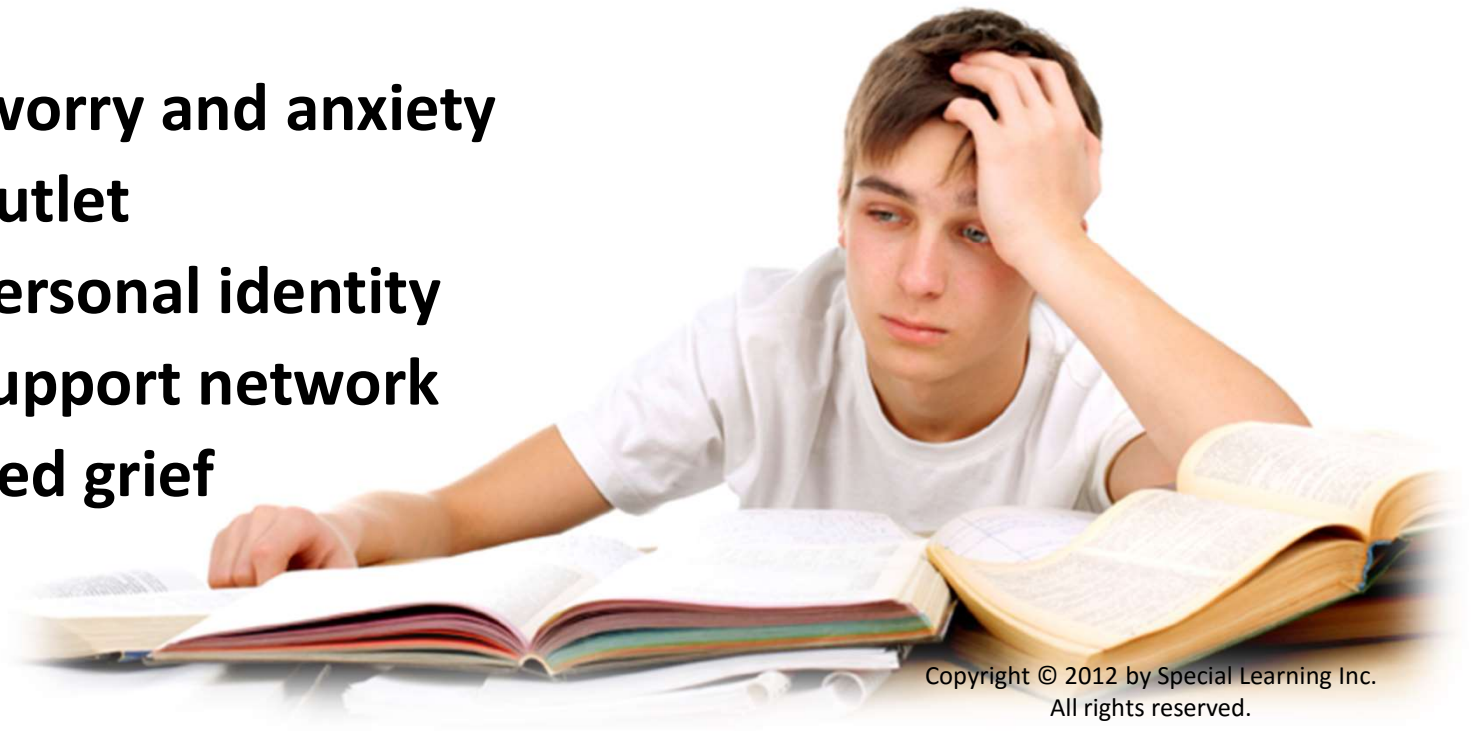
The ABC's of Economics

- Cost of care and treatment
- Make too much for help but too little to afford it alone
- Finding qualified providers that accept Medicaid rates
- Insurance limits and discrimination
- Finding debt
- Red tape
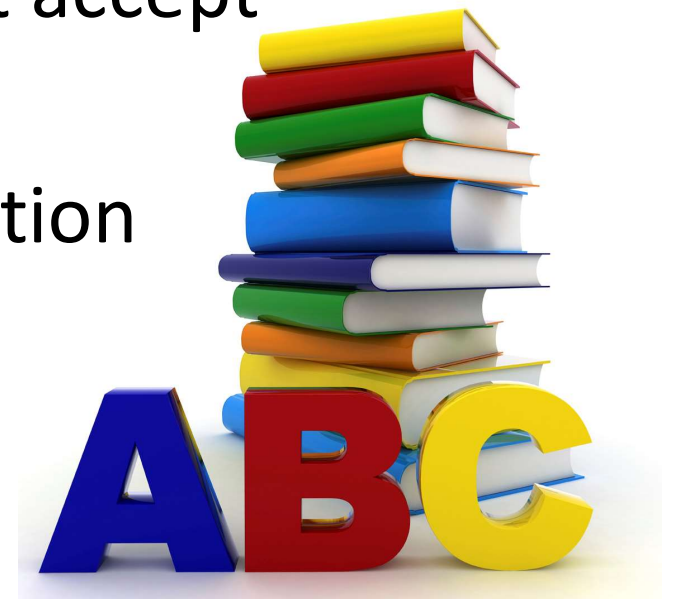
Politics 101

- Pay now or pay later?
  - The state budget dilemma
  - What research tells us
- Educate and advocate
  - Parents have the strongest voice
  - Legislators
    - Senators
    - State Representatives
  - Decision makers
- Pass the buck…
  - Learning disorder, medical disorder, mental health disorder, or developmental disability?
  - Who claims it pays

Recommended Treatments for Autism

- Intensive behavior intervention (IBI)
  - 47% of children successfully mainstream
- Speech therapy
- Occupational therapy
- Physical therapy
- Medication, as appropriate

Recommendations for the Family System

Know Intensive Behavior Intervention (IBI) is the most successful, evidence-based treatment. Based upon research, 47% of children receiving early IBI become indistinguishable from their peers. ***Start treatment EARLY!***

Link with professionals who are experts in autism treatment and service supports

Connect with reliable local and national information systems such as

> OCALI
> Step By Step Academy
> Special Learning
> Autism Speaks
> Autism Society of America

Practice behavioral intervention procedures and apply them consistently in the home with the help of a Board Certified Behavior Analyst®

Join parent groups

Understand you are the strongest voice for your child

Learn to advocate

Take care of yourself... use support professionals such as social workers and therapists
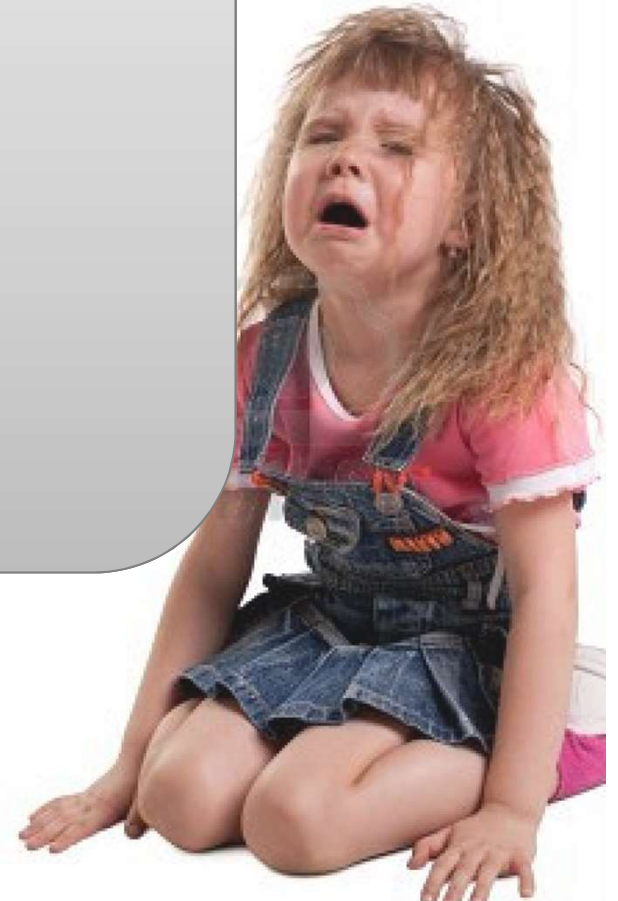
Realize the impact this will have on the entire family

Recognize you are not alone

Difficulties of Finding Treatment

- Lack of visible resources for treatment, education, and funding

- Misdiagnosis reported higher in minority groups

- Diagnosis often comes later in minority groups

  o Lack of early intervention

Some Possible Support Services

- Medicaid and state waivers

- Food stamps

- Transportation

- Social Security benefits

- Prescriptions

- Diapers, home supplies

- Medical, dental, vision care

- Case coordination

Federally Mandated Requirements

- EPSDT - Early Periodic Screening Diagnosis and Treatment

- IDEA - Individuals with Disabilities Education Act

- FAPE - Free & Appropriate Public Education

Birth to 3 Program

- Help Me Grow
  - Early intervention
  - Behavior assessment
  - Speech therapy
  - Occupational therapy
  - Case coordination
  - Linkages to other support systems
  - Other assessments

The School System

- 3 years old through 22nd birthday

- IDEA & FAPE

- Sometimes difficult to work with

- Not trained in most effective autism treatments

- Lawsuits

- Multi-factored evaluation (MFE); Evaluation Team Report (ETR)

- Individualized Education Plan (IEP)

- Advocacy

- Scholarships: District no longer responsible
  - o Autism Scholarship Program (ASP)
  - o Jon Peterson Scholarship

The Work Force

- **Vocational assessment, training, and coaching**
- **Soft skills**
- **How do adults feel productive and/or find employment?**
- **What jobs are available?**
  - **Moderate to high functioning**
  - **What happens to those who can't work**

Adult Living

- Independent living
  - Employment
  - Money & budget management
  - Safety and support network
  - Social network

- Group home living
  - How employment affects financial supports
  - Support staff
  - Boundaries

- At home with parents
  - What happens when parents are no longer able to care for their child?

Working with Adults with Autism

- **When working with the adult**
  - Adults with ASD may experience a greater sense of isolation and difficulty with social relationships and intimacies
  - Those with Asperger's may do well in "system-centered" jobs
- **When working with the parent(s) and families**
  - Autism affects the entire family unit
  - Strains on relationships and family member can cause tension
  - Depression and financial concerns are often present
  - Caregiver burnout and social isolation is a factor in participation in services
- **System problems**
  - Unprepared for the growing population
  - Lack of understanding around the diagnosis
  - So many questions
  - Not set up for the complexities and needs of individuals with autism
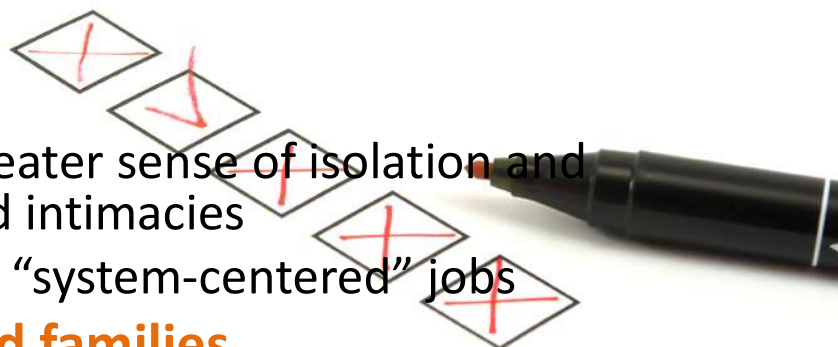
When there's nowhere else to go…

- Intensive care and/or residential
- Helping parents make the choice
- Understanding the multiple treatments that may be needed
  - Behavior intervention
  - Communication training
  - Independent living skills training
  - Medication management
  - Recreation activity and opportunity
  - Socialization
- If one has a waiver, the waiver is put on hold

Beliefs, Norms & Subcultures

Autism Community Subsection

Parents and Families

The Single Parent

Minority Groups

- African Americans

- Hispanic & Native American

- Somali and various African Cultures

- Asian cultures

Autism Community

The Autism Rights Movement
- Provider sensitivity
- Encourages society to accept people with autism "as they are" without modifying behaviors
- Believe society should learn to tolerate harmless behaviors
- *Many people disagree with the movement because of their views of the "gifts" associated with autism and the possible jeopardizing of funding and treatment*

African Americans

- Mistrust of systems

- Low expectations for quality care

- Still view Mental Illness as a moral issue and weakness

- Tend to lean more toward faith and/or cultural traditions for healing than to seek out doctors, therapist, etc.

- Lack of access to or unfamiliar with educational, diagnostic, treatment and medical services

- Belief that discipline not treatment is needed
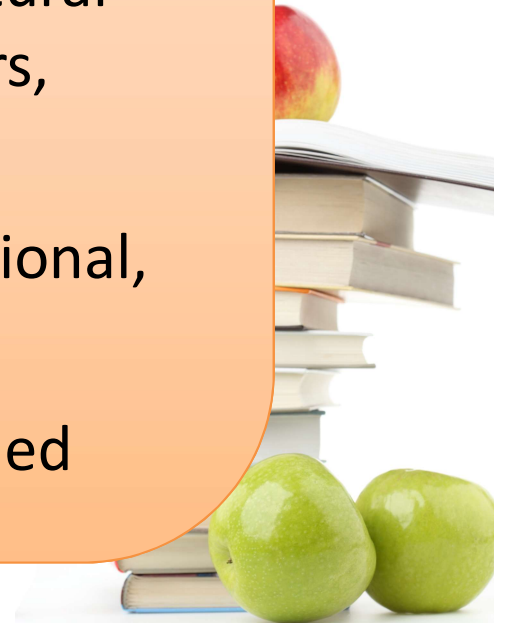
Hispanics & Native Americans

Mistrust of systems

Low expectations for quality of care

Still view Mental Illness as a moral issue and weakness

Tend to lean more toward faith and/or cultural traditions for healing than to seek out doctors, therapists, etc.

Lack of access to or unfamiliar with educational, diagnostic, treatment and medical services

Some report that 50% of children with autism are not diagnosed leading to delayed services and intervention

Somali or
Various African Culture

- Mistrust of systems

- Language barrier

- Still view Mental Illness as a moral issue and weakness

- Tend to lean more toward faith and/or cultural traditions for healing than to seek out doctors, therapists, etc.

- Belief that a special needs child is a personal failure as a mother

- Tendency for fathers to blame the mother for not birthing a "normal" child

- Avoidance of diagnosis due to shame and fear

- Belief that mental illness is possession or an angry spirit which requires spiritual healing

Asian Cultures

- Strict social standards on acceptable behaviors

- Extended family plays a large role with parent

- Social pressure on parents regarding child

- Lower rate of understanding in Indian countries

- Problems with misdiagnosis in Indian cultures

- Societal lack of awareness and resources to treat autism

Beyond Case Coordination: *A Closing*

- *More than a case coordinator:* social workers possess unique skills that may impact the treatment of autism
- Provide therapy to both the family and the child
  - Family needs: *treat the system*
    - Grief and coping strategies
    - Sibling therapy
    - Parent training
    - Diagnosis and treatment education
  - Child needs: *treat the mental illness*
    - Help achieve basic needs like communication
    - Build cognitive processes through therapy
    - Provide behavior reduction & self-monitoring interventions
    - Help them impact their environment with social skill training and practice
    - Facilitate independent living skills

Blessed are those who stop and listen to my chatter. You may not understand me; but I love when people talk to me, for I long for companionship, too.

Blessed are those who take my hand and walk with me when the path is rough, for I easily stumble and grow weary. But thank you, too, for letting me walk alone when the path is smooth, for I must learn independence.

Blessed are those who take the time to tell me about special happenings, for unless you make special effort to inform me, I remain ignorant.

Blessed are those who wait for me. I may be slow, but I appreciate your patience.

Blessed are those who are not ashamed to be seen in public with me, for I did not choose to be born thus. It could have been you as well.

Blessed are those who do not pity me, for I don't want pity. All I want is understanding and respect for what I have learned as well.

Blessed are those who notice my accomplishments, small as they may seem to you. I must work long and hard to learn many of the things you take for granted.

Blessed are those who include me in their games, even though I may not understand the rules, I still like to be included in your activities.

Blessed are those who think of me as a person who loves, and hurts, and feels joy and pain just like you do, for in that respect I am normal.

-Author Unknown