TEACCH Approach to Working with Families in a Multicultural Context

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Goals:
- To introduce the TEACCH Autism Program philosophy regarding working with parents.
- To discuss the obstacles and barriers to obtaining diagnostic evaluations experienced by families from a variety of cultural backgrounds and develop awareness of cultural considerations when working with families during the diagnostic process.

Resources
- Maureen Morrell & Ann Palmer
  Parenting Across the Autism Spectrum: Unexpected Lessons We Have Learned (2006)
- Lee Marcus and Ann Palmer
- Mary Van Bourgondien
  Challenges Faced by Families of Children and Adults with ASD: What Professionals Should Know (2016)

University of North Carolina
TEACCH Autism Program
- Part of the UNC-Chapel Hill School of Medicine and NC AHEC Program
- Pilot project in 1960s, created by Dr. Eric Schopler and Dr. Bob Reichler
- TEACCH Executive Directors
  - Dr. Eric Schopler
  - Dr. Gary Mesibov
  - Dr. Laura Klinger

University of North Carolina
TEACCH Autism Program

MISSION STATEMENT
The University of North Carolina TEACCH program creates and cultivates the development of exemplary community-based services, training programs, and research to enhance the quality of life of individuals with Autism Spectrum Disorder and their families.
UNC TEACCH Autism Program
Services Across the Lifespan
- Diagnostic Evaluations
- Intervention Services
- Adult Services
- Professional Training and Consultation
- Research

Clinical Services Across the Lifespan
- Diagnostic Evaluations
- Toddlers up through adulthood
- Intervention Services:
  - Early intervention, in-home and center based
  - Parent teaching/coaching
  - School-aged intervention groups
  - Adult counseling

TEACCH Autism Program
Adult Services
- Carolina Living and Learning Center (CLLC)
  - An integrated vocational and residential program for adults with ASD.
- Supported Employment program

TEACCH Autism Program
Intervention Philosophy
- Family collaboration
- Whole person view
- Learning styles and differences
- Structured TEACCHing

Historical attitudes of professionals toward parents of children with autism
- Psychogenic views dominant in the 50s and 60s blaming parents for the child’s autism
- Behavioral strategies developed at that time that put the burden of stringent intervention protocols on the parents

TEACCH Autism Program
- Research project in 1966, Schopler & Reichler
- Initial research demonstrated that parents of children with autism were effective co-therapists in working with their children.
- Parents as co-therapists is the foundation of TEACCH
**Family Collaboration**
- Provide support
- Parent implemented interventions
- Source of information

**Family Support Services**
- Mothers Support Group
- Fathers Support Group
- Parent Discussion Group
- Parent Mentor Program
- Home TEACCHing kits
- Referral to community resources

**Parent Implemented Interventions**
- Learning Style of Autism
  - Understanding this individual’s strengths, challenges and learning needs
  - Goals set in collaboration with parents
  - Organizational skills
  - Adaptive Behavior
  - Social skills and behaviors
  - Emotional Regulation
  - Communication

**Parent Implemented Interventions**
- Structured Teaching
  - Visual information
  - Visual Schedule
  - Work Systems
  - Making the world predictable
  - Clear expectations
  - Individual Sessions
  - Group Sessions
  - Clients of All Ages

**Integration of a variety of intervention models**
- Social Thinking (Michele Garcia Winner)
- Facing Your Fears (Judy Reaven et al)
- Early Start Denver Model (Rogers, Dawson)
- Parent Child Interaction Therapy (Eyberg)
- T-STEP (TEACCH School Transition to Employment & Post-Secondary Education)
- Other Cognitive Behavior Therapy techniques (e.g., coping strategies)

**Family Collaboration in Diagnostic Process**
- Referral
- Source of information
- Parent checklists
- History forms
- Parent interview
- For young children, parents participate in evaluation (administration of diagnostic and developmental measures)
Obstacles to timely diagnosis of ASD

- Lack of awareness of developmental norms and differences
- Lack of screening as a standard pediatric practice
- Lack of understanding and acceptance within the family or the community

ASD Prevalence: 2012
children born 2004 across the ADDM Network

Identification of ASD is
1.2x more likely among white than black children
1.5x more likely among white than Hispanic children
4.2x more likely among boys than girls

ASD Prevalence: 2012
children born 2004 in North Carolina

Identification of ASD is
1.2x more likely among white than black children
2.1x more likely among white than Hispanic children
4.6x more likely among boys than girls

Families from non-dominant cultures, may face additional obstacles to early diagnosis of ASD
A somewhat different process may be more in keeping with their cultural values
Multi-culturalism

- What does this mean to us?
- We tend to think of race, country of origin, language spoken in the home as defining cultural background

Culture as a broader concept

- Race/ethnicity
- Country of origin
- Language & dialect spoken at home
- Socio-economic or class status
- Geography – rural vs. urban vs. suburban
- Educational background/literacy
- Personal & family history
- Life circumstances

We all belong to more than one culture!

We cannot generalize!

- We can’t assume that we understand an individual family’s perspective on the basis of
  - Our own history and experience
  - General or prior knowledge of other families with some cultural similarities

Language Concerns

- A family in which no adults speak English face a huge barrier to medical and other services
- Asking questions or even knowing where to direct your questions is much more complicated if you don’t speak English or have an interpreter
- Navigating the system is already hard, much harder in a foreign language, even with the support of an interpreter

Spanish-speaking families

- Today 9% of NC residents are Hispanic/Latino compared to 1% in 1990
- About half were born in the US and about half were born in other countries
- Of those families, 81% speak a language other than English in the home
- Because of these trends, there are now more services available in Spanish than in the past
- It is helpful to be part of a larger community of people who speak your language
But Remember!

- People we might perceive as being culturally similar may have quite different experiences
- There are many different Spanish dialects
- Some families come from areas where indigenous languages – NOT Spanish – are spoken
- Families are different from each other in terms of education and background, even from the same country

Language Concerns

- May be even more problematic for families who are not part of a larger community speaking their language
- May be harder to find interpreters
- Harder to find written information and other resources in that language
- May be less likely to find other families of children with disabilities who speak their language

Working with an Interpreter

- If at all possible, the interpreter should not be a family member
- If one parent speaks English and the other does not, it is still helpful to have an interpreter
  - Avoids putting English-speaking parent in a dual role of parent and interpreter; he or she can focus on receiving information rather than on translation
  - May be helpful for the English-speaking parent to hear the information in both languages

Working with a child whose first language is not English

- If the child comes from a home where English is not spoken, it is helpful if the person working directly with the child speaks the family’s language.
- If the child is very young and/or non-verbal, it may be possible for the examiner to learn the needed words to conduct the assessment.
- Older children who have been in school may be fluent in English even if their parents are not.
### Considerations around race/ethnicity

- Well documented that African-American and Native American families often have less access to health care.
- This may also be true for other groups such as recent immigrants.
- Professionals may not have the time to establish a trusting relationship.

### Considerations around Poverty

- While poverty cuts across ethnic and racial groups, we know that children from minority cultures are more at risk for living in poverty.

<table>
<thead>
<tr>
<th>Race/Culture</th>
<th>Percentage of Children Living in Poverty</th>
</tr>
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<tbody>
<tr>
<td>African American</td>
<td>36%</td>
</tr>
<tr>
<td>Native American Indians</td>
<td>34%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>31%</td>
</tr>
<tr>
<td>Asian</td>
<td>13%</td>
</tr>
<tr>
<td>White</td>
<td>12%</td>
</tr>
</tbody>
</table>

*From the Annie E. Casey Foundation, based on US Census information*

### Poverty creates significant barriers

- More likely that all the adults in the home are working at jobs that don’t allow vacation or other time off with pay: every professional appointment means a loss of income.
- Transportation:
  - In town, may have cumbersome and inconvenient public transportation.
  - In rural areas, no public transportation.
  - Medicaid transportation.
- Primary care is more likely to be provided by an agency such as the Health Department or a community health care agency.
- Children who are seen by different providers over time are less likely to receive adequate screening for ASD.
Poverty creates significant barriers

- May or may not have insurance or Medicaid
- Many private providers do not accept Medicaid
- Even if you have insurance, many providers require that families pay in full up front then get reimbursed by insurance
- Often there are so many stressors (financial, emotional, time) on the family that they may not be able to prioritize seeking a diagnosis or services for the child

Geographic Barriers

- Families who live in rural areas are farther away from available services, including primary care, and face more challenges in accessing those services
- Time required to get there and back home
- Transportation issues

Cultural beliefs and attitudes

- Some non-western or minority cultures are more accepting of interpersonal differences than dominant western culture
- Often there is a religious aspect to a family’s attitude towards a child with a disability
  - “Gift from God”
  - Personal satisfaction from the caregiving relationship
  - Preference for traditional healers and practices

Cultural beliefs about disabilities

- Conversely, there may be stigma associated with disability
- In some cultures, it is particularly difficult to have a son with developmental problems
- History of over-identification of children of color placed in special education settings in the past may cause some families to be reluctant to have their children identified

Beliefs and Attitudes

- Some cultures may place more emphasis on language and social interactions while others emphasize independent skills

Considerations for professionals in the diagnostic process

- Be thoughtful about our own background and beliefs, our assumptions, our implicit bias; be aware of how our own ideas and previous experiences may be affecting our interactions with the family
Considerations for professionals in the diagnostic process

- Be flexible
  - May be more difficult to contact, to schedule
  - May not fit into the typical time frame
  - Ask parents how we can make the process more accessible for their family
  - If the family already works with a trusted professional or support person (e.g., church or community member), get a signed release and collaborate with that person to help the family feel more at ease with your process.

Considerations for professionals in the diagnostic process

- Try to develop an understanding of the family’s community. Some families may be part of a tight-knit group that provides support and community advocates.

Considerations for professionals in the diagnostic process

- Avoid assuming that we know what is going on with the child; we may recognize behaviors and interaction styles, but we need to slow ourselves down in our interactions with parents.

Considerations for Diagnostic Interview with EVERY Parent

- We can’t assume that we understand the family’s background, values, beliefs or perspectives
- We can’t assume the family has the same goals we do
- Approach each family individually with a spirit of humility and curiosity
- Always start by asking the parents about their concerns, their questions, their understanding of the child
- LISTEN

Considerations for Diagnostic Interview

- LISTEN
- Withhold judgment
- Ask follow-up questions based on what the family actually said, not on our own perspective or understanding
- There’s a fine line between being interested and being intrusive

Considerations for Diagnostic Interview

- Sometimes a family comes to us because somebody else has a concern and they may not (e.g., the pediatrician referred for an evaluation although the parents believe everything is fine)
- If we clearly see the behaviors of concern, we may feel tempted to jump right in and list those out for the parents
- DON’T GIVE IN TO TEMPTATION! There will be a better outcome if we take a little more time with the parents
Considerations for Diagnostic Interview

- Move from discussing specific behaviors toward general information about ASD.
- That is, ask about specific behaviors without labeling them or offering a judgment about the implications of those behaviors until the parent asks for that information. Try to stay focused on observable behaviors rather than interpretations of behaviors.

Considerations when working with the Child

- Take enough time with the child.
- If the parents’ referral concern is that the child is not talking, but the professional concern is around ASD, take some time before bringing that up. You may want to plan the next time when you will see the child rather than talking about ASD right away.
- One of the most frustrating things for parents is having somebody work with their child for an hour then diagnosing ASD.

In the end.....

- Just like every person with ASD, every family is unique.
- Approach each family with an attitude of openness, curiosity, empathy.
- Listen without judgment.
- Use everyday language to give information to families.
- Make sure your feedback is tailored and specific to this individual.

Sampling of Reference Articles


Sampling of Reference Articles

Other Resources


Websites:

- AutisminBlack.com
- www.AmericanImmigrationCouncil.org
- www.census.gov/quickfacts
- www.pewresearch.org