Multi-Cultural Considerations: Co-Occurring Down Syndrome and Autism Spectrum Disorder
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DS-ASD as Co-Occurring Diagnoses
• Prevalence is underestimated by many providers
• Diagnosis of ASD occurs at a later age than when ASD alone
• ASD symptoms often attributed to delay, medical complications, DS
• Increased family challenge to communicate regarding both diagnoses

DS-ASD as Co-Occurring Diagnoses
• Medical needs may be a priority over mental health challenges
• DS support groups and resources don’t address the challenges of ASD
• Families often have limited knowledge about ASD, strategies and resources
Culturally Aware Providers

• Engage families
• Increase access to services & intervention
• Support communities
• Impact development
• Increase likelihood of positive outcomes

Learning Objectives

• Understand, respect and appreciate cultural diversity through understanding of definitions and cultural exploration
• Increase knowledge of barriers to providing culturally relevant intervention strategies
• Expand intervention strategies through use of resources, family and community strengths

Learning Objective #1

• Understand, respect and appreciate cultural diversity through understanding of definitions and cultural exploration
Mental Health: A Report of the Surgeon General

- Disparities for minorities in MH services
  - Racial and ethnic minorities have less access to MH services than whites
  - Less likely to receive needed care
  - When they receive care, more likely to be poor in quality.

- Source: Dept. of Health and Human Resources A report of the Surgeon General (2001)

Importance of Language

- The Surgeon General’s Report on Mental Health: Culture, Race and Ethnicity concluded that culture matters in how ethnic minorities fail to access or confront barriers when trying to obtain help. In particular, the report noted “a major barrier to effective mental health arises when provider and client do not speak the same language.”


Language

- Verbal and non-verbal means of communicating and sharing information and meaning
- Common understanding of language and communication supports intervention
Definitions

• Culture
  – A shared set of norms, beliefs, values, customs, rituals

• Ethnicity
  – The state of belonging to a social group that has a common national or cultural tradition. Ex: homeland, ancestry, history

• Race
  – A group of people of common ancestry, distinguished by physical characteristics

Definitions

• Subculture
  – A cultural group within a larger culture, often having beliefs or interests that vary from those of the larger culture

• Culture is often different within an ethnic group
  – E.g. different tribes or subgroups

• Can vary by geographical location

Cultural Exploration

• Demystify cultural conversation
• Ask questions
• Know and share your culture
• Learn and explore
• Know your community
  – Community events
Exploring Beliefs of Origins

- Genetic
- Environmental toxin
- Shots
- Gift/blessing from God
- Punishment from God
- Illness
- Birth trauma

Exploring Beliefs of Intervention

- Belief systems
- Herbal interventions
- Spiritual healers
- Community elders
- No need for intervention
- What does improvement look like

Strategies

- Thoughts and questions for providers to explore with families and caregivers
- Information for families and caregivers to share with providers
Don’t Assume…

• Listening is agreement
  – It may be respect
• Agreement is understanding
• Trust
• Sharing information is comfortable or easy
• Family decision making roles

Conversations Between Provider & Family

• What is your preferred name to be called?
• What name should I call your child?
• What is your cultural identity and what words do you use to describe it?
• What languages are spoken in your home, family and social community?
• Who lives in your home and are there others who care for your child?

Conversations Between Provider & Family

• Tell me about your experience getting to this community
  – Where there challenges for you
  – Where there challenges for your child
  – What have you found to be helpful
  – What has been difficult
• Have you had any experiences where you felt you were treated differently due to who you are?
Conversations Between Provider & Family

- Does your family have a specific belief system, spiritual practice or faith tradition?
- Are there rituals and traditions that are important to you and your family?
  - Can you help me understand them?
- How are decisions made within your home and family about parenting?

Conversations Between Provider & Family

- Why did you come to (agency/school/etc.)
- How do you understand where these challenges came from/originate from?
- Tell me about your experiences/thoughts about mental health services (school, county).
- Is anyone supporting you in getting services?
  - Who, may I connect with them?

Learning Objective #2

- Increase knowledge of barriers to providing culturally relevant intervention strategies
Barriers

• Challenges to be decreased and eliminated
• Discussion points/action items within agencies, schools, care systems
• Topics to address with families and caregivers

Barriers

• Community
• Provider availability
• Compatibility of western MH with cultural expectations
• Expectations from the provider/family encounter
• Services to match cultural believes
• Language/interpretation

Barriers

• Individual beliefs
• Lack of awareness of our own culture
• Uncertainty related to exploring other cultures
• Fear of insulting others’ beliefs and ideas
  – Political correctness
  – Seek clarify from others
Barriers – To Access

- Discrimination
- Language interpretation availability
- Expected family follow up from providers
- Family unfamiliarity with how to access system
- Provider effectiveness of communicating regarding services appropriate and available

Barriers – Western System

- Waitlists
- Complexity of system
  - Western culture is primarily siloed
    - Schools
    - County
    - Mental health
    - Medical
- Immigration challenges
- Lack of trust
- Isolation
- Insurance
- Transportation
- Complexity of documentation
  - Forms not translated
- Diagnostic language
  - Autism isn’t a word in several languages
- Documentation status

Barriers – Individuals

- Family/client history
  - Refugee
  - Trauma
  - Individual journey
  - Fear for safety
  - Deportation fears
- Family holidays/traditions
  - Not attending services on holidays
Barriers – Individuals

- Experience with mental health systems
  - Positive/negative
  - Confusing/clear
  - Meet expectations?
  - Useful
  - Match with parenting style

Strategies

- Identify barriers within your own belief system
- Identify barriers within your organization
  - Assess wait times
  - Evaluate outcome results
  - Look at cancel/fail rates
  - Determine if length of treatment differs

Strategies

- After barriers are identified create active process for change
  - Open discussion about how to change systems
  - Timelines for implementation of change
  - Reassess degree of change & if it created a new barrier
Learning Objective #3

• Expand intervention strategies through use of resources, family and community strengths

Intervention Strategies - Resources

• Family strengths as resources
• Resources within your organization
• Community resources
  – Know resources for specific cultures in your community
    • What do they provide
    • How can families access them

Strategies – Interpreters

• Before the appointment/meeting
  – Take time to meet with interpreter to communicate type of appointment they will be interpreting
  – Set expectations for the role
  – Discuss technical terms that may be used
  – Discuss sensitive topics that may come up
  – Ask questions to assist you in effective communication
Strategies - Interpreters

- During the appointment/meeting
  - Explain confidentiality
  - Identify interpretation needs and make plan for interpretation
  - Face family and speak to them (not to interpreter)
  - Avoid metaphors, jargon, acronyms

- During the appointment/meeting
  - Allow time to talk about how concepts are understood
  - Allow time for interpreter to understand concepts and explain to family
  - Be open to and allow time for interpreter to explain cultural concepts when word for word translation is not adequate

Diagnostic Considerations

- Ask questions about general ideas
  - Behavior observed
  - Sequences of development
- Clarify if the behavior and development is within expectations for the culture
- Consider "symptoms" within the expectations of culture to determine relevance for diagnoses
Diagnostic Considerations

• Psychological testing
  – Awareness of appropriate assessment tools
  – Use of interpreters
  – Expanded caregiver interview
  – Explanation of results
    • Concepts, behaviors & development vs. testing & diagnostic language
    • Culturally integrated information

Intervention Considerations

• Has provider clearly outlined their role, functions and services?
• What does the family consider improvement/progress?
  – What are expectations
• Ask family if they want their cultural traditions and rituals incorporated into services

Adapting Strategies to Match Family Strengths & Culture

• Down syndrome - autism spectrum disorder
  – Social
  – Play
  – Communication
  – Behavior
  – Daily functioning
Intervention Considerations

• Social
  – Discuss expectations for eye contact
  – What is family’s social goal for child?
  – Determine expected social actions within the community
  – Outline social expectations within your setting (e.g. school, agency)

• Play
  – Toys available to family
  – Are toys within your setting culturally sensitive?
    • For example – dolls, animal figurines
  – What is family play goal?

• Communication
  – Language – what language(s) will child learn & be exposed to
  – Visual supports
    • Insure that pictures are culturally sensitive
    • Picture schedules
    • Visual routines
    • Daily tasks such as bedtime, toileting, etc.
  – Transition visuals
    • Daily schedule
Intervention Considerations

• Behavior
  – Learn what is acceptable to family
  – Understand family process for behavior management
  – Educate family on Down syndrome and ASD behaviors

Intervention Considerations

• Daily Functioning
  – Determine family needs
  – Address safety needs
    • Games – stop/go
    • Reverse hide & seek
  – Meal time challenges
    • Family meal times vary greatly
    • Consider family foods
    • Discuss meal time expectations

Summary

• Goal for providers is cultural competence
• Learn about your own culture
• Explore other cultures
• Be open to new perspectives
• Identify and remove barriers
• Utilize resources
• Adapt strategies/intervention to meet each child/family need
### Resources

- **CDC – Center for Disease Control**
  - Free Spanish translation on website
  - cdc.gov
- **Down Syndrome Association of Minnesota**
  - dsamn.org
- **Fraser**
  - fraser.org

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### Resources

- **SPAN – Somali Parents Autism Network**
  - spanmn.org
- **Family Voices of Minnesota**
  - familyvoicesofminnesota.org
- **Autism Society of Minnesota**
  - ausm.org

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### Resources

- **When Down Syndrome and Autism Intersect: A guide to DS-ASD for Parents and Professionals**
  - Margaret Froehlke, M.R. & Robin Zaborek