

Module 7:

Barriers to Care: Working with Families who have children with ASD Diagnosis

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Introduction

- “Welcome to Holland” or parental expectations
- Family barriers
- Family Navigator role
- ASD
- Considering culture in ASD
- Exercise

Family barriers

Child behaviors	Homelessness/Housing issues
Migratory status	Food insecurity
Transportation	Other children with disabilities
Language	Domestic violence
Lack of family support	Isolation/Depression
Money	Lack of knowledge/insecurity

Family Navigator Role

- Build Relationships
- Empower and support families by building self-efficacy
- Provide education and information
- Problem-solve barriers
- Navigate families through the health care system and through community-based systems to help access services
- Manage and organize information with families
- Provide Referrals: parental mental health and sibling health

Health Disparities in ASD

- The goal of Family Navigation is to reduce and eliminate differences in rates of ASD screening, diagnosis and access to services by race, ethnicity, language, socioeconomic status.

Racial and ethnic disparities in diagnosis

Identification of ASD in Massachusetts¹

- Average age of diagnosis is 25.6 months for MA children served by EI
- Incidence rate is one in 85 (MA DPH, 2013)
- However, certain populations of children still do not receive timely screening & evaluation. These include²:
 - Children from families with English as secondary language
 - Children from families who are foreign born
 - Children whose mothers are under the age of 24

1. Retrieved: www.amchp.org/programsandtopics/CYSHCN/projects/spharc/peer-to-peer-exchange/Documents/State%20Template_MA.pdf

2. Early Diagnoses of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001–2005, Manning et al., 2011

Why was my child diagnosed with ASD and what does it mean?

- Cultural issues
- Stages of reaction
- Services and resources

Challenges with the term “autism”

- English: Autism
- Hmong: Ib qho kev tsis taus uas yog puas rau phab kev nrog lwm tus tham thiab koom nrog lwm tus...Kev tsis taus no yuav tshwm sim tawm rau thaum muaj hnub nyoog 3 xyoos thiab yuav muaj mus tas lub neej. Hom uas tshwm sim tsis loj yog hom hu ua Aspe
- Somali: Cilladaha ootiisamku waxaay saameyn karaan maskaxda. Waxa dhacda in carruuraha qaba cilladaha ootiisamku sida ay bulshada ula dhaqmaan, hadlaan, ama u fakiraan ay ka duwan tahay carruuraha kale. Marxalado aad u adagna yeelan karaan
- Spanish: Autismo

Interpreting autism: Lost in translation. <http://umtia.org/wp-content/uploads/2015/04/ASD-Culture-FINAL.pdf>

Cultural barriers

▣ Challenges with the term Autism

Cultural barriers

▣ Family and community

Cultural barriers

▣ Community partner: Early Intervention

Cultural barriers

▣ Migratory status

Maternal blame and stigma

▣ Maternal blame and stigma

Stages of family response

- Shock
- Sadness or grief
- Anger
- Denial
- Loneliness
- Acceptance

Case study: Sharon and Sam

- Sharon lives with her mother, 2 siblings and her 18 months old son Sam. She's a single mother and father is not involved. Sharon just started college and has a part-time job at a coffee shop. Her family and friends help her watching Sam but there's no consistency and sometimes she struggles to find someone to watch him. Sharon is struggling to schedule EI services because Sam doesn't have a permanent day care and her mother says that Sam is a normal child, boys are slower than girls and all his uncles started talking after they turned 3yo. Grandmother refuses to follow EI recommendations and this is a source of tension between them.

Case study: Carmen and Carlos

- Carmen is a 40 yo mother living with her 2 children and their father in a Section 8 apartment. Her partner is the Section 8 voucher holder, he's on disability and is alcoholic. Carlos is 24mo and was diagnosed with ASD a month ago. Carmen is a recovering drug addict who lost the custody of her older sons to the state when they were 5 and 7, they grew up in foster care as they were never adopted, they are adults now and keep in touch with Carmen. Carmen doesn't want to fail again but her partner wants her to drink with him, she obliged sometimes because gets mad otherwise. Carmen behaviors are erratic, sometimes she calls crying and yelling and sometimes is extremely calm and composed. Carmen struggles with Carlos behaviors, he doesn't like to get out of the house and his behaviors get worse when they take public transportation. Last week she had an argument with a passenger who told her to "control your kid!". Carmen is worried about getting EI services at home, being reported and losing the custody of her children again.

Case study: Diana and Daniel

- Diana and her husband have two boys, their youngest Daniel was diagnosed yesterday. You met Diana at her house and she is devastated and doesn't believe the diagnosis, she wants to know exactly what the doctor saw in Daniel, why he got the diagnosis. She keeps talking and says she won't disclose the diagnosis to anyone, she lives surrounded by her husband family and she doesn't want them to know, especially since a month ago they went to a family gathering and Daniel disappeared and they couldn't find him.

When they were just about to call the police one of the kids found Daniel hiding in a closet playing with his "Thomas the Train" toys, that's the only toy he likes. Since then her mother in law has been asking and making remarks that no one on their side of the family has "mental retardation". Diana is reluctant to get EI because she thinks that having people coming in and out of the house would raise more questions. She doesn't want to attend any other family function and feels isolated because all her family is in Venezuela and they come to visit every other year.

Case study: Phoebe and Patricia (and Paige)

Patricia is a 25mo twin who was diagnosed with ASD 2 weeks ago. Her sister Paige was also assessed but she received a diagnosis of Global Developmental Delay. Phoebe doesn't understand how Patricia got the diagnosis when Phoebe is the one who looks "autistic". She thinks both twins complement each other and she wants them both to receive the exact same services. She wants you to help her to fire her current EI provider and find another provider who is willing to provide the same services to both children.

Questions?

References

Manning, S. E., Davin, C. A., Barfield, W. D., Kotelchuck, M., Clements, K., Diop, H., ... & Smith, L. A. (2011). Early diagnoses of autism spectrum disorders in Massachusetts birth cohorts, 2001–2005. *Pediatrics*, peds-2010.