I declare I have no financial or other conflict of Interest

CASE PRESENTATION: HOW CULTURE AND LANGUAGE AFFECT NEURODEVELOPMENTAL DISORDER DIAGNOSIS AND SERVICE ACCESS

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ABSTRACT

Neurodevelopmental Disorder such as Autism spectrum disorder (ASD) or Intellectual Disability (ID) affects people of all backgrounds, ethnics, heritages, and cultures. Children from minority or immigrant families experience significant practical and cultural barriers to mental health access. Ethnic and cultural background affect family members' perception of social and communication impairment, in addition to interpretation of developmental delay, stigma and belief of cause, and decision making on treatment. Both language and cultural factors create extra challenges regarding application of diagnostic criteria to a non-English speaking patient, collaborative evaluation from multiple disciplines, psychoeducation on family members, and exploration of culturally compatible and/or language competent service.

CASE

Patient is a 21-year-old Hispanic male who lives with his mother, stepfather in MA. Initial evaluation was conducted at the UMass Center for Autism and Neurodevelopmental Disorders (CANDO) clinic by an interdisciplinary team, composed of a Speech/Language pathologist, an Occupational Therapist, a Child Psychiatrist, and a resource specialist. A Spanish interpreter was present in all the meetings since both parents were Spanish speaking only.

Psychiatry History:

- Significant for ADHD, receptive and expressive language delay, moderate Intellectual Disability (IQ estimated to be in the 40s), and a diagnosis of Autism Spectrum Disorder.
- Worsening mood dysregulation in the past 6 months that led to severe behavioral challenges, with concern about possible psychotic symptoms at points.
- Has been on a combination of 3 anti-epileptic medications for several years. Ritalin LA and Clonidine for ADHD and impulsivity. About 8 months ago Ritalin LA was exchanged for Concerta because of insurance coverage issue, which roughly coincided with the parental report of increased behavior dysregulation (defiance, aggression towards his parents, self mutilation, and disorganization).
- He is a bilingual, multimodal communicator, who uses single words, gestures, pointing and facial expression to communicate. Parents understand 0-60% of his communication, while the interpreter only understands 10% of his Spanish. Uses single word in English, with functional language skills estimated by SLP to approximate 24-42 month level.

Medical History

- Hx of complex partial seizure with secondary generalization
- Cyclic vomiting with hx of vomiting episode evolved into a complex partial seizure
- Hemiparesis of left nondominant side since 2007, after an episode of status epilepsy (Inpatient hospitalization x 1month)

Family Psychiatric History

- Intellectual Disability, ADHD, developmental delay runs in the extended family on both sides

Social History

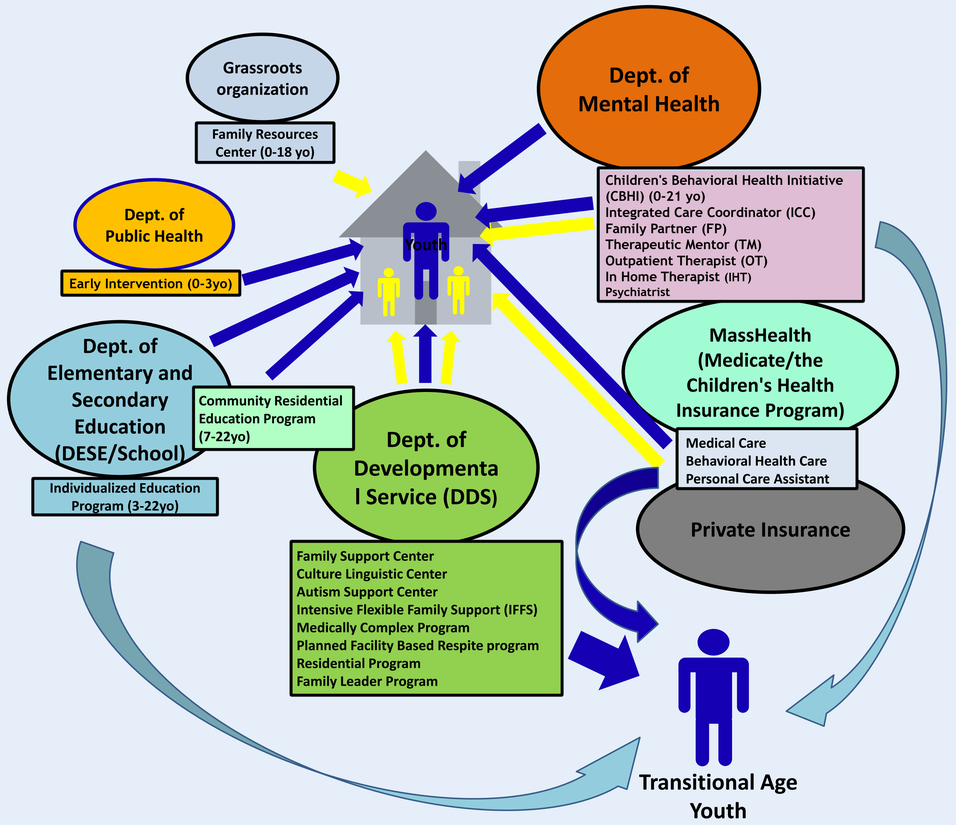
- Born in Puerto Rico. The mother divorced his bio father when he was 7yo, and moved to US in 2014.
- Has 44 hours of PCA support at home during the week.
- Community support from the local church.
- Hx of verbal and emotional abuse during his childhood.

Developmental History

- Regression across development skills including toilet training, gross and fine motor skills, language skills.

Education History

- In his last year of Secondary Education, before aging out of public school system. No definitive transition plans in place.



BACKGROUND INFORMATION

Report of 2014–2016 National Health Interview Survey (NHIS) for diagnosed autism spectrum disorder, intellectual disability, and other developmental delay among children aged 3–17 years

- Hispanic children (4.69%) were less likely to have been diagnosed with any developmental disability compared with non-Hispanic white children (7.04%), non-Hispanic black children (6.20%), and non-Hispanic other children (6.16%)

ADDM Network ASD surveillance in 2012 continues to indicate disparities in estimated ASD prevalence by race/ethnicity

- Non-Hispanic black and Hispanic children were less likely to have a first evaluation by age 36 months, and Hispanic children were less likely to have a previous ASD diagnosis or clarification

Latino children with ASD with severe limitations received fewer specialty autism-related services (Behavioral intervention, OT, Social skills) than their white peers

- Minority community and families have limited flexible resources (i.e. knowledge, beneficial connections)
- Immigration Status might prevent help seeking
- Lack of empowerment and advocacy skills in these families
- Language barrier
- Limited culture competence training in health care and service providers
- Socioeconomic disadvantages

Transitional Age Youth with ASD who were racial/ethnic minority averaged 3 more unmet services need in their last high school year, relative to youth who were white/non-Hispanic.
Disparities in service access might be magnified even more after high school exit, lead to further decreased adult outcome

CHALLENGES/RECOMMENDATION

Services:

- **Previous psychiatric service closed their practice** - f/u with a provider at CANDO Transitional Youth Clinic (Switch his stimulant back to Ritalin LA; Consider a trial of antipsychotic)
- **Age out of his current pediatrician's service** - Refer to family medicine provider with experience working with individuals with developmental disabilities
- **MassHealth is no longer cover home ABA services after age 21** - Assist with financial subsidy application for private insurance
- **School is planning to take speech therapy off his IEP** - A comprehensive SLE in both Spanish and English; A conversation book composing photos and topic boards in English and Spanish
- **Will age out of secondary education when he turns 22** - Provide resources and information about transition to adulthood planning in Spanish; Encourage family to work with school on transition preparation. i.e. visit highly structured day programs
- **Recommend school OT evaluation to assess regulation needs and ability to assess curriculum**

Parents' Concerns:

- **Home behavior management -** assist to resume home based behavioral therapy service
- **Safety concern** (self injury, aggression, socially inappropriate sexual behaviors, and risk of being victimized) - Information about 911 indicator program, handicap placard.
- **Psychoeducation**
- **Recommend to review the recommendation with his Spanish speaking Case Manager.**

Patient's Goal: To wear a cap and gown at his graduation ceremony - A support letter to school

TREATMENT COURSE

The 1st week

- Continue with disruptive behavior - Calm self down when parents called 911
- One ER visit due to dehydration secondary to vomiting - Sent home after negative work up.
- Family meeting with the team for recommendation

The 2nd week

- Follow up with a fellow at Transitional Youth Clinic.
  Waiting for insurance approval for Ritalin LA
  Will consider starting antipsychotic until approval from his neurologist

The 4th week

- Second feedback meeting with the SLP.
  The parents have been trying to use Google translator to understand the initial recommendation report in English -The SLP asks the interpreter to read and translate the whole recommendation
- Patient was switched from Concerta to Ritalin LA upon its approval.

The 6th week

- Second f/u with the fellow at Transitional Youth Clinic
  Parents noticed behavioral improvement.
  Not willing to start an antipsychotic despite of his neurologist's approval
  Continue to work on the rest of the recommendations

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