Autism Family Navigation & Project EARLY

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MA Act Early Summit
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BOSTON UNIVERSITY

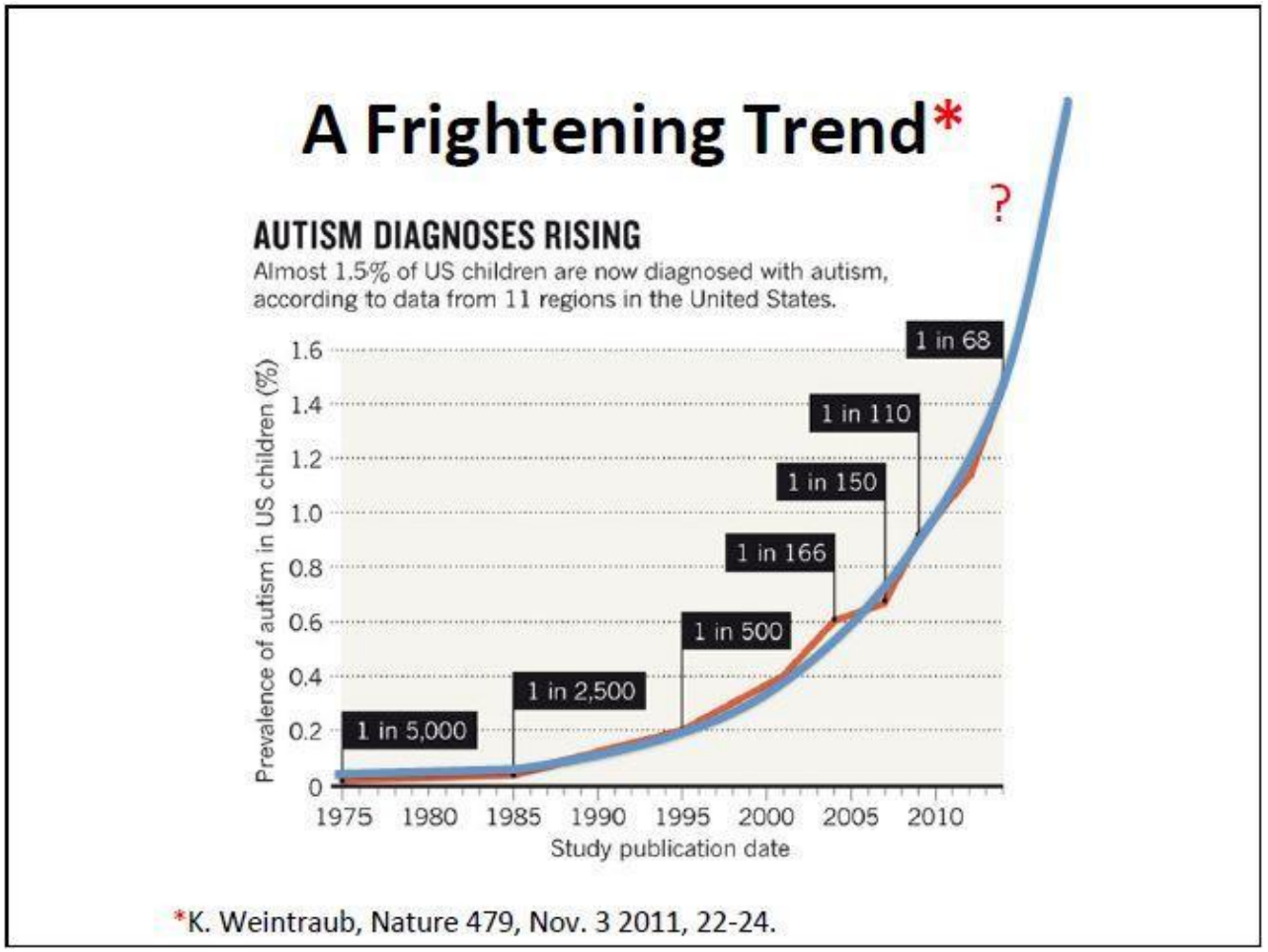
BOSTON MEDICAL CENTER
EXCEPTIONAL CARE. WITHOUT EXCEPTION.

Family Navigation

Background
"what do we know"

- Prevalence of autism spectrum disorders increasing over last decade
  - Income and services
- Increased recognition of importance of early evidence-based treatment
- Disparity in low income and minority communities in timing of ASD diagnosis and in receipt of services

Rising prevalence of ASD



Disparities in diagnosis

- Black and Latino children get diagnosed later than white children
- More misdiagnosis for low-income children and minority children
  - Other behavioral diagnoses: ADHD, Oppositional Defiant Disorder
- Less severe cases of autism more often missed in minority populations

Complex Issue

- Families often must identify services, follow through with applications and coordinate care
- Families may experience high levels of stress
- Low income minority populations may face additional challenges- linguistic and cultural barriers, financial constraints, transportation issues, limited social networks

Questions

"what do we need to know?"

- As more treatment options available, how to support ALL, not just resourced, families in accessing intervention and learning lifelong advocacy ?
- How can this be done using a culturally and linguistically competent, family centered approaches?
- Can we adapt approaches used in other medical conditions that may have existing research base?

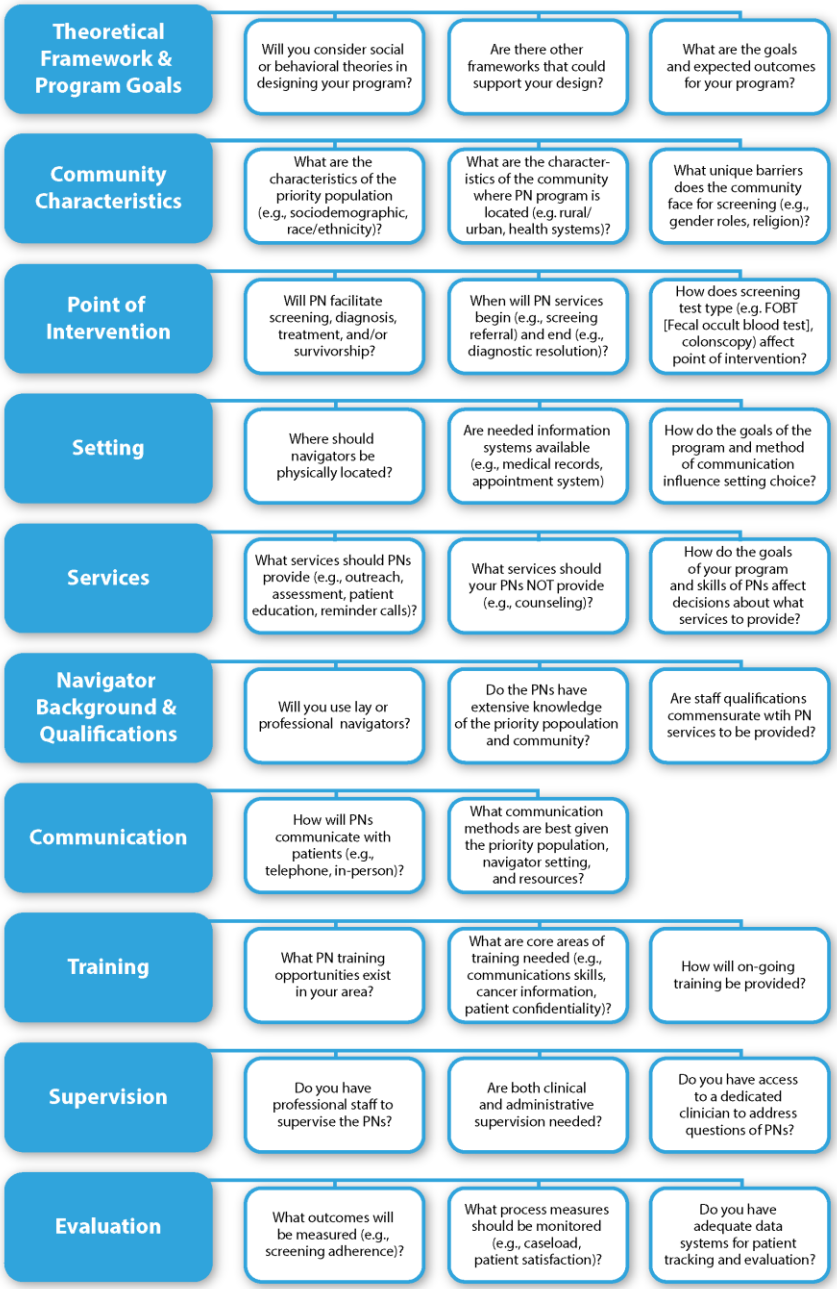
Patient Navigation

- Area of care management that aims to reduce disparities
- Used primarily in adult oncology
  - Patient Navigation Research Program (PNRP)
    - Balogh EP, et al. Patient-centered cancer treatment planning: improving the quality of oncology care. Summary of an Institute of Medicine workshop. Oncologist. 2011;16(12):1800-5.
- On review, efficacy for patient navigation in increasing adherence to diagnostic follow-up care after detection of an abnormality

Defining Patient Navigation

- Individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience.

Association of Oncology Social Work, http://aosw.org/docs/PR-PositionPatientNav.pdf



Amy DeGroff, Ph.D., M.P.H., Key Considerations in Designing a Patient Navigation Program for Colorectal Cancer Screening, APHA, 2013.

Navigator model in ASD

- Time-limited care management strategy that focuses on addressing patient-specific barriers to a defined set of services
- Navigation in Autism involves 2 important modifications:
  - Changing the setting to pediatrics and shifting model from *patient* to *family*
  - Navigating just medical system barriers to also navigating community and educational barriers

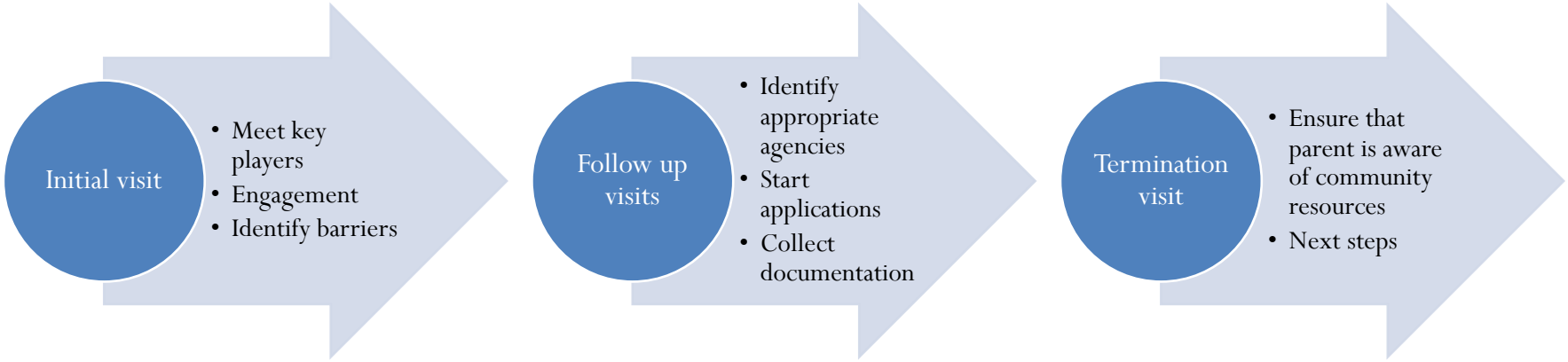
Family Navigation: Core Concepts

- Identification of those at risk
- Identification of individual barriers to care through a culturally competent approach
- Development and implementation of plan to overcome those barriers-with provider team
- Tracking problems to resolution
- Visits may take place at home, clinic, school/EI, SSI office, by phone, email, etc. depending on families needs

The Navigators

- Members of community with diverse backgrounds
- Undergo
  - In-house training: ASD, resources, service systems, shadow FN, clinic observation, Motivational Interviewing
- Multiple languages: Spanish, Haitian Creole, others with interpreters

Navigation timeline



Termination visit

John Doe		
Exit Interview - April 29, 2016		
(Entrevista de salida)		
Service Servicio	Status Status	Pending Gestiones pendientes
Department of Developmental Services (Departamento de Servicios para el Desarrollo)	Caseworker: Debby DDS 617-555-5555	
Public School (Escuela)	May Institute (Out-of-District placement)	Dr. BMC will check his IEP to check if aditional services are needed.
SSI	Gave mom resources and copies of DBP reports to apply for SSI.	N/A
CBHI	Referrals made: 1. ICC-Agency 1- Referral rejected because he "only has an ASD diagosis" 2. ICC- Agency 2 - Don't have opening 3. IHT-Agency 3- Rejected because case is too complicated and should be an ICC	Needs to talk with PCP and Dr. DBP
Medical Care		Dr. DBP would like to see John in 6 months (October 2015), please schedule appointment.
PCA	9.30 hours approved.	Renewal is due in May. Sylvia PCA Support Services Manager Phone 781-555-5555 Fax 781-555-5555
For follow ups		
Para seguimientos		
Dr. DBP	617.414.0000 Fax: 617.414.7915	DBP@bmc.org
To schedule appointments	Jahna	(617) 414-4841, Option #2 then #3
Boston Medical Center Autism Resource Specialists	Liz Ferriero	Elizabeth.Ferriero@bmc.org 617-414-3698
	Lauren Bartolotti	Lauren.Bartolotti@bmc.org 617.414.3698

Family Navigation ASD initial studies

	#1: FN after new ASD dx (n=192)	#2: FN after a referral to developmental clinic (n=40)	#3: FN after a failed screen in primary care (n=40)
Study design	Randomized trial; FN vs usual care	Pilot RCT; FN vs usual care	Pilot RCT; FN vs usual care
Age range	≤ 8 years	≤ 6 years	≤ 3 years
Study sample	Low income, minority	Low income, minority	Low income, minority
Intervention start and end points	New ASD dx – 6 months post dx	BMC DAC referral – diagnostic resolution	Failed screen – diagnostic resolution
Primary outcomes	Time to receipt of recommended services; parental mental health	Time from referral to diagnostic resolution; parental mental health	Time from referral to diagnostic resolution; parental mental health

Family Navigation ASD initial studies: Results

	#1: FN after new ASD dx	#2: FN after a referral to developmental clinic	#3: FN after a failed screen in primary care
Intervention delivery	Phone contacts: 20.5 In-person visits: 4.8	Phone contacts: 3 In-person visits: 4	Phone contacts: 15 In-person visits: 4
Outcomes	We observed differences in how US and non US born caregivers understood, described, and disclosed their child's ASD diagnosis.	95% of FN families vs. 53% of UC families completed the developmental assessment; Average time to diagnosis: 146 days (≈ **5 months**)	90% of FN families vs 60% of UC families completed the developmental assessment; Average time to diagnosis: 76 days (≈ **2.5 months**)

Topics addressed by Family Navigators

- 85% of intervention families faced five or more barriers to care
- Four categories account for 50% of these barriers
  - Understanding the objectives of the assessment
  - Completing paperwork required for assessment process
  - Scheduling and attending appointments
  - Individual barriers such as transportation and childcare

Project EARLY

Early identification and service linkage for young children at risk for Autism Spectrum Disorders

PI: Emily Feinberg

This project is funded by the National Institute of Mental Health

Rationale for Project EARLY

- Evidence that early identification and engagement in services can change course of disorder
- Screening tools exist but are not used consistently
- Current age of diagnosis >3 years
- Multiple systems barriers to diagnostic evaluation and services

Background

- Target population
  - Low-income, racial and ethnic minority, urban children
  - Age between 15-27 months
  - All languages
- Primary care based systems intervention
- Sites
  - Boston
  - CHOP
  - Yale

Specific Aims

Assess the superiority of FN as compared to CCM as a means to:

- Achieve an 80% screening rate for indicators of ASD across all sites;
- Implement a decision rule for referral to ASD evaluation;
- Shorten the time to diagnosis among children suspected to have ASD;
- Shorten the time to deployment of ASD services among those diagnosed;
- Improve engagement with ASD services

Improving Screening and Identification

- Activity/Intervention:
  - Activated versus standard of care screening with M-CHAT @ 18 & 24 months at well-child visits
  - Confirmatory screen (M-CHAT Follow-Up Interview) conducted by research staff
  - Refer children with + confirmatory screen for expedited evaluation
- Outcomes
  - 90% of eligible children screened
  - 90% of confirmatory screens completed
  - Fast-track referral – first appointment scheduled within 30 days

Improving Diagnosis and Linkage to Services

- Activity/Intervention:
  - Family navigation or CCM provided from time of baseline and ending 100 days post diagnostic resolution

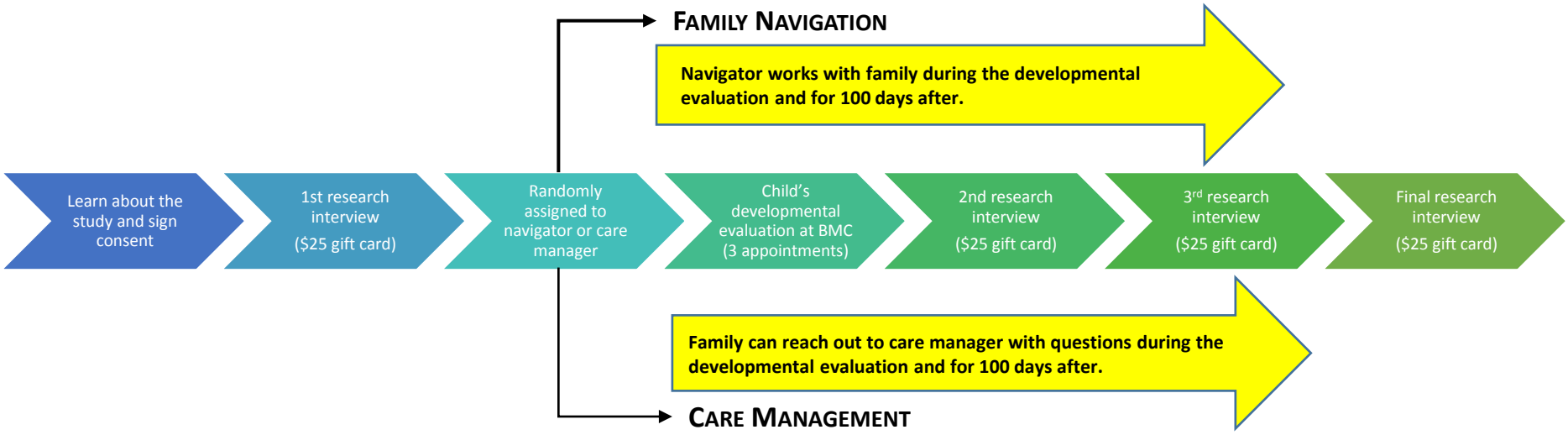
- Outcomes
  - Increase proportion of families who complete diagnostic evaluation
  - Increase proportion of families who receive ASD specific services within 60 days from time of diagnosis
  - Increase proportion of families who receive recommended services within 100 days of diagnostic resolution

Family Navigation vs Conventional Care Management

- Family Navigators
  - Provide individualized support to families
  - Available during routine and off hours (evenings, weekends)
  - Meet families in the community, accompany to appointments
  - Trained in motivational interviewing
  - Have regular supervision meetings with DBP

- Care Managers
  - Based at BMC and available for parent-initiated support
  - Do not provide support off-site or off hours

Project EARLY study timeline



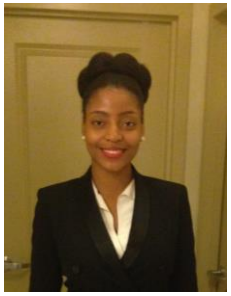
Project EARLY

Who are the Boston navigators?

Ivys Fernandez-Pastrana, JD
*Spanish-speaking

Betsy McGovern, BS

Yaminette Linhart, MSW MPH
*Spanish-speaking



Mitsouka Exantus, BA
*Haitian Creole-speaking

Current status

- Currently in Y2 of a five year grant
- 87 families enrolled across all three cities (goal n=250)
- ~60% of those who have completed evaluations have received an ASD diagnosis so far

Our ultimate goal

- Five years from now, at the end of the grant period …..
  - Integrated set of strategies
  - Known effectiveness – for whom and in what settings
  - Scalable and ready to be implemented

Enters the Family Navigator

- Navigating a family or "how to be a detective"
- "You never know what's waiting for you" or surprises during home visits
- When the diagnosis is not the problem or "I need to complete the requirements of my housing program within the next month or we will be evicted"

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

Navigating a family or “how to be a detective”

- Creating your own support network
- Getting to know community resources
  - Networking
  - Listserves
  - Conferences, talks, support groups
  - Webinars

“You never know what’s waiting for you” or surprises during home visits

- Poverty and its challenges
- Safety during home visits
  - Check-in person
  - Inside a house
- When your client “disappears”

When the diagnosis is not the problem or “I need to complete the requirements of my housing program within the next month or we will be evicted”

- Confusing governmental programs
- When to empower and when to DIY
- How much information is too much information?

Case study: Brenda and Bella

- Brenda moved to your state from Florida five months ago and has been living with her sister. She is 7 months pregnant, has a five years old daughter and a 20 months old daughter: Bella. During the diagnostic visit she tells you that she had an argument with her sister the week before and she moved out. She went to the Department of Temporary Services and was placed in a shelter 90 minutes away from the hospital, she was able to come to this appointment because someone from the shelter gave her a ride. She's living in a hotel room without access to a kitchen, only has a microwave and Bella is refusing to eat anything but milk. EI services were interrupted because the shelter is outside their catchment area. She is overwhelmed, tired and not interested in starting with a new EI agency. She has cardiac issues and is worried about her prenatal care and following up with her cardiologist.

Case study: Amina and Ali

- Amina has been living in the US for 3 years with her husband and three children. A week after the diagnosis she tells you that her husband doesn't believe the diagnosis and their families back in their country are blaming her for the diagnosis, they say she's making the child sick and her husband says she's pretty much on her own, he's not opposing services but she is the only one in charge of coordinating care. She is very well educated and believes the diagnosis (to her the diagnosis is a confirmation that she wasn't imagining things) but feels lonely. Two weeks after the diagnosis she calls you very early in the morning, she's at a local hospital because her husband assaulted her, she has 2 broken ribs and significant bruises in her face. She's crying and tells you she doesn't know anyone else in the US and doesn't know what to do.

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: Carla and Carlos

- Carla is a 40yo 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. Carla 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 Carla. Carla doesn't want to fail again but her partner wants her to drink with him, she obliged sometimes because gets mad otherwise. Carla behaviors are erratic, sometimes she calls crying and yelling and sometimes is extremely calm and composed. Carla 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!". Carla 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's 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.