

SaLSA

**Screening and Linkage to Services for
Autism (SaLSA): Study of Patient
Navigation for Low Income Families**

Carolyn DiGuseppi, MD, MPH, PhD

Presentation Plan

- Introduce study partners
- Describe study background, aims and design
- Present preliminary results

University of Colorado Anschutz Medical Campus



Colorado School of Public Health, JFK Partners,
and Schools of Medicine and Nursing



DENVER HEALTH

Level One Care for ALL

- Comprehensive, integrated health care system located throughout Denver
- Largest provider of health care to Medicaid beneficiaries and uninsured patients in Colorado

Rocky Mountain Human Services (RMHS)



- Community-based, non-profit
- Provides Part C Early Intervention (EI) services for infants and toddlers from Denver County
 - Identification, care coordination, development of Individualized Family Service Plans (IFSPs), provision/ support for EI services
- Specialized clinical team evaluates children for autism spectrum disorder (ASD) using standardized testing



Welcome to El Grupo VIDA!

For people with disabilities or special needs who are Hispanic/Latino

DONATE NOW

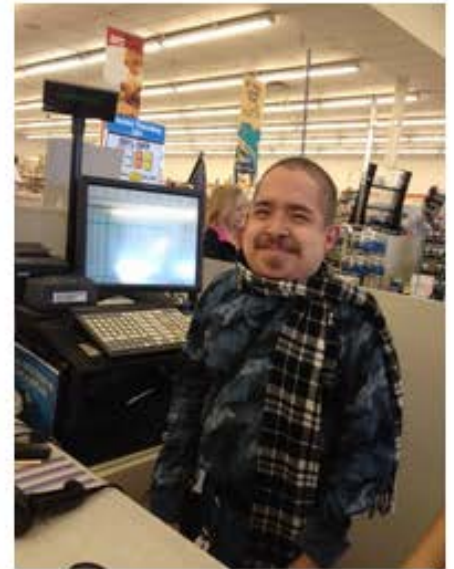
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"We are in this together!"



Overcoming Disabilities with Love

El Grupo VIDA is a network of Hispanic/Latino parents formed to provide mutual support for people with disabilities or special needs, their parents, family, and guardians.



Study Team

- University of Colorado Anschutz Medical Campus
 - Colorado School of Public Health
 - Carolyn DiGuseppi, MD, PhD (PI)
 - Kathryn Colborn, PhD
 - Yurico Gutierrez
 - School of Medicine / JFK Partners
 - Cordelia Robinson-Rosenberg, PhD RN
 - Kristina Hightshoe, MSPH
 - Steven Rosenberg, PhD
 - College of Nursing
 - Jacqueline Jones, RN, PhD

Denver Health Medical Center

- Margaret Tomcho, MD, MPH, MBA
- Silvia Gutiérrez-Raghunath, MBA (Patient Navigator)
- Anita Roberts, RN
- Kristin Breslow, Analyst

Rocky Mountain Human Services

- Jodi K. Dooling-Litfin, PhD
- Beth Scully
- Lindsey Krings

El Grupo VIDA

- Jeanette Cordova

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Screening for autism spectrum disorder (ASD)

- Young children with ASD can benefit from early detection, treatment and services
- Most children with ASD not diagnosed until after age 3 years
- Routine screening in primary care improves early recognition
- CDC and American Academy of Pediatrics recommend screening all children for ASD at 18 and 24 months
- Even among children who screen positive for ASD, many do not receive referrals for evaluation, undergo diagnostic evaluations or engage in services and treatment for ASD

Early identification and treatment of ASD

- Minority, foreign born, less educated and low-income populations:
 - Receive referral, diagnosis and treatment less often and later
 - Report having:
 - less information about how to obtain care
 - more problems obtaining care
 - fewer support services to connect them to care
 - less satisfaction with EI services

Patient Navigators



Lurie Center, Autism Speaks

- Trained to address and overcome barriers to care
- Guide patients with positive findings (e.g., + screening test) through and around system barriers to help ensure timely diagnosis and treatment
- Shown to improve management of chronic conditions in adults and delivery of preventive care in children

SaLSA Study Aims

- **Aim 1: Using a randomized controlled trial design, test the effect of autism patient navigation on ASD referral, diagnostic evaluation, and linkage to services in a minority, disadvantaged population**
- **Aim 2: Examine the reach, implementation and potential for adoption and long-term maintenance of autism patient navigation in clinical settings serving a minority, disadvantaged population**

Setting: Denver Community Health Services

- Network of 25 community and school-based health centers located throughout Denver that provide primary care
- Children seen at Denver Health: >90% Medicaid / Medicaid eligible; 74% Hispanic, 10% Black
- 7 primary care clinics and 2 school-based health clinics implemented ASD screening

Routine ASD Screening

- ASD Screen at 18- and 24-month well visit
- Modified Checklist for Autism in Toddlers-Revised with Follow-Up (M-CHAT-R/F): two-stage parent-report screening tool to identify young children at risk for ASD

0-2 Low Risk

3-7 Moderate Risk

8+ High Risk

- If <24 months, repeat at 24-month well visit
- Otherwise, no further evaluation

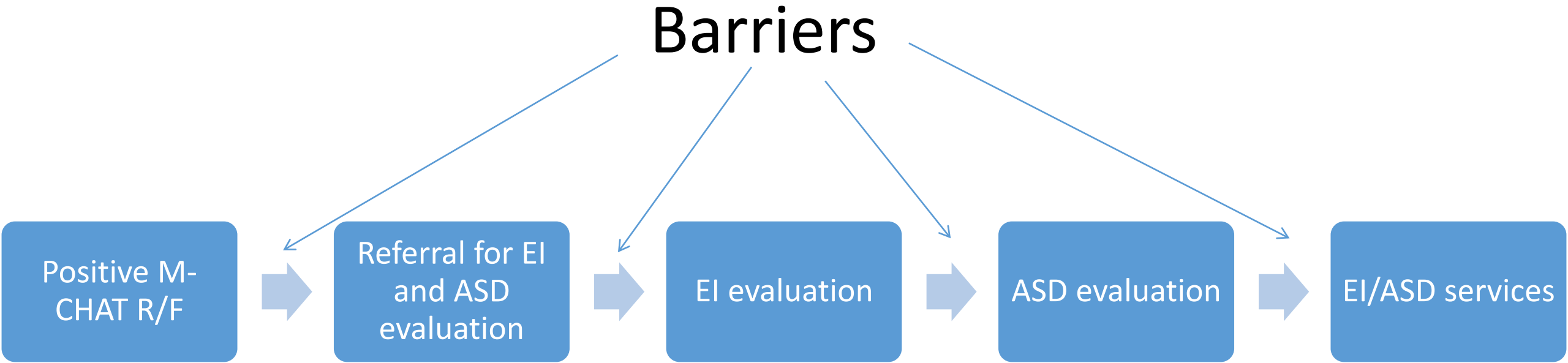
- Implement M-CHAT-R Follow-Up Interview
- If positive (>1), **referred for ASD evaluation**

- **Referred for ASD evaluation**

Screening to Services Flow



Screening to Services Flow



How can the Autism Patient Navigator (APN) help?

- Overcome system barriers (e.g., promoting referral, coordinating care with service providers)
- Overcome individual barriers (e.g., transportation)
- Educate families and providers about ASD, tests and treatments
- Offer psychosocial support to families

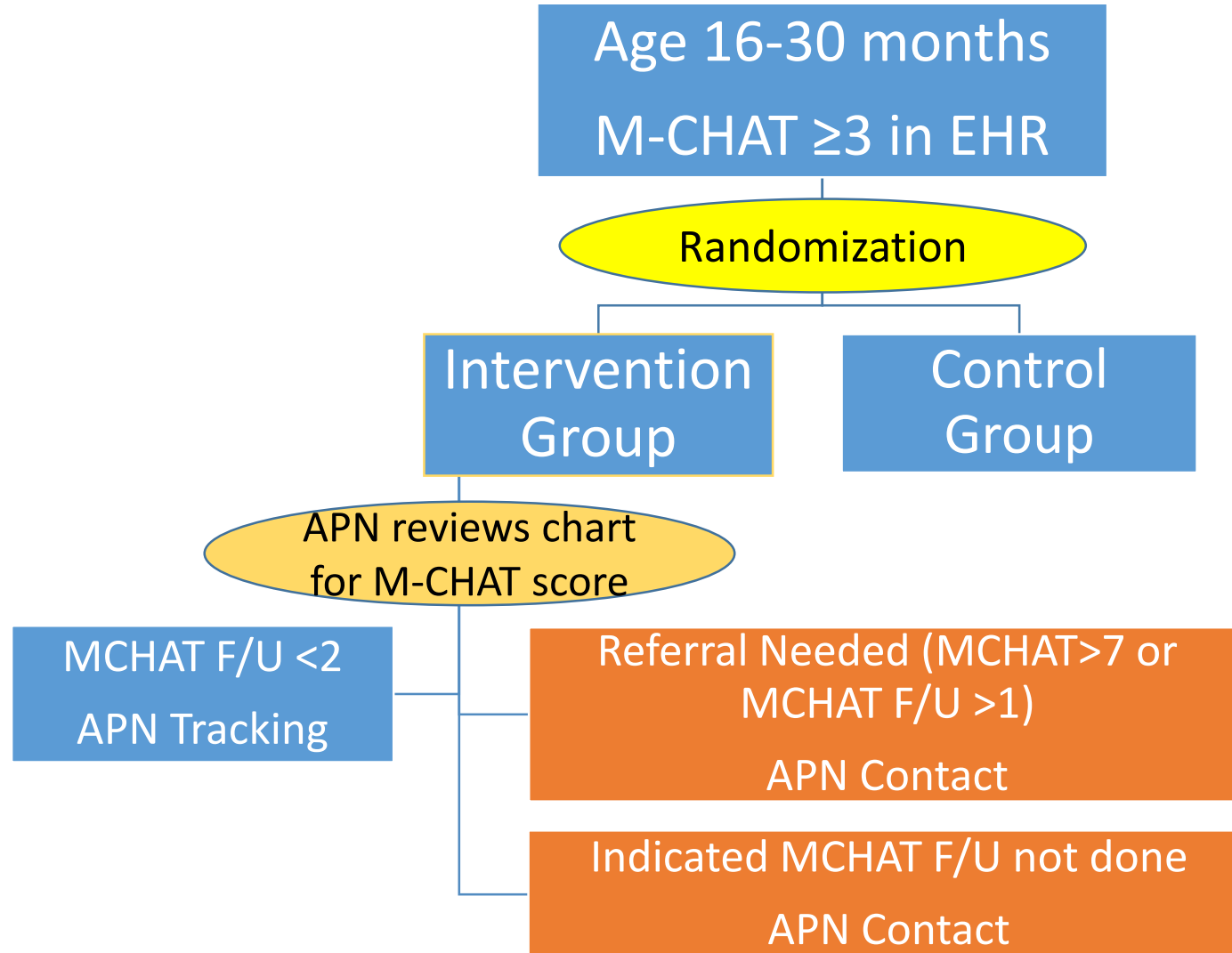
Autism Patient Navigator Training

- Patient navigator training, including modeling, practice and feedback
 - Communication and problem-solving skills
 - Finding and evaluating patient resources
 - Providing support, education, and coaching for caregivers
 - Coordinating care among providers, agencies and organizations
- ASD presentation, screening, diagnosis, treatment and prognosis
- Orientation to Part C Early Intervention services and RMHS

Study Population

- Inclusion:
 - Children aged 16-30 months
 - Seen for well visit at DH primary care clinics
 - Positive initial M-CHAT-R (score ≥ 3 ; moderate or high risk) recorded in the Electronic Health Record
- Exclusion:
 - Existing ASD diagnosis
 - Not resident of Denver County

Study Design: Randomized Controlled Trial



Autism Patient Navigator Procedures

- If indicated M-CHAT Follow-up not done, contact provider/ staff as well as the family to recommend and promote completion
- If M-CHAT score indicates need for referral and ASD evaluation:
 - Contact family, obtain consent and interview family about barriers
 - If indicated referral for ASD evaluation not made, contact provider / staff to ensure referral
 - Provide family with assistance, resources, and education about ASD and EI
 - Maintain ongoing communication and support

Primary Outcomes (Aim 1)

- Effect of APN on occurrence, age and timing of M-CHAT follow-up interview, referral for evaluation, eligibility determination, ASD diagnosis, and initiation of EI services, in intervention vs. control group
- Assessment of barriers to referral, diagnostic evaluation, and initiation and engagement in services, in intervention group

Secondary Outcomes (Aim 2)

- *Reach*: Proportion and representativeness of intervention group children whose families engage with the patient navigator
- *Implementation*: Scope and volume of APN activities
- *Adoption and Maintenance*: Staff, provider and family attitudes and perceptions about autism patient navigation

Data Sources

- Linked electronic health and early intervention services records
- Standardized semi-structured interviews with parents in intervention group, at the time of consent and after Individualized Family Service Plan (IFSP) meeting
- Patient navigator records – barriers identified, APN activities
- Key Informant (KI) Interviews
 - Parents of children allocated to receive APN support
 - Clinical and EI providers and staff
 - Study team

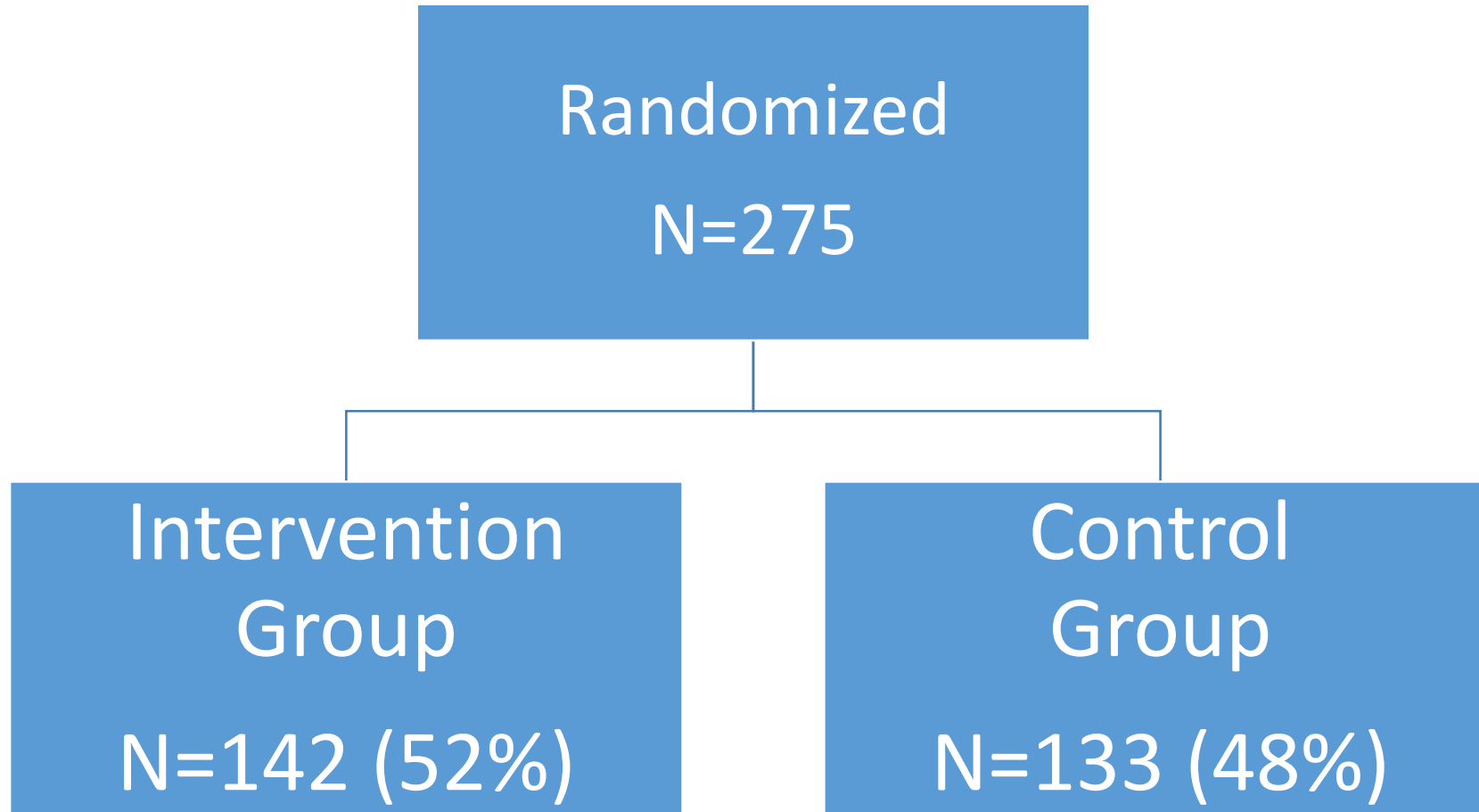
Analysis Plan

- **Descriptive statistics on participant characteristics (preliminary data)**
- Hypothesis testing using regression models
- **Tabulation and summary of barriers experienced by families consenting to APN (preliminary data to date)**
- **Tabulation of APN activities (preliminary data to date)**
- Qualitative analysis to examine feasibility and acceptability of APN

Presentation Plan

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Children with Initial Positive M-CHAT Screen Randomized to Study Groups



Demographic Characteristics by Study Group*

	Intervention	Control
Age (mean)	21.4 mo	20.8 mo
Male	62%	64%
Race		
White Race	47%	54%
Black Race	21%	18%
Other Race	32%	28%
Hispanic Ethnicity	61%	59%

*Preliminary

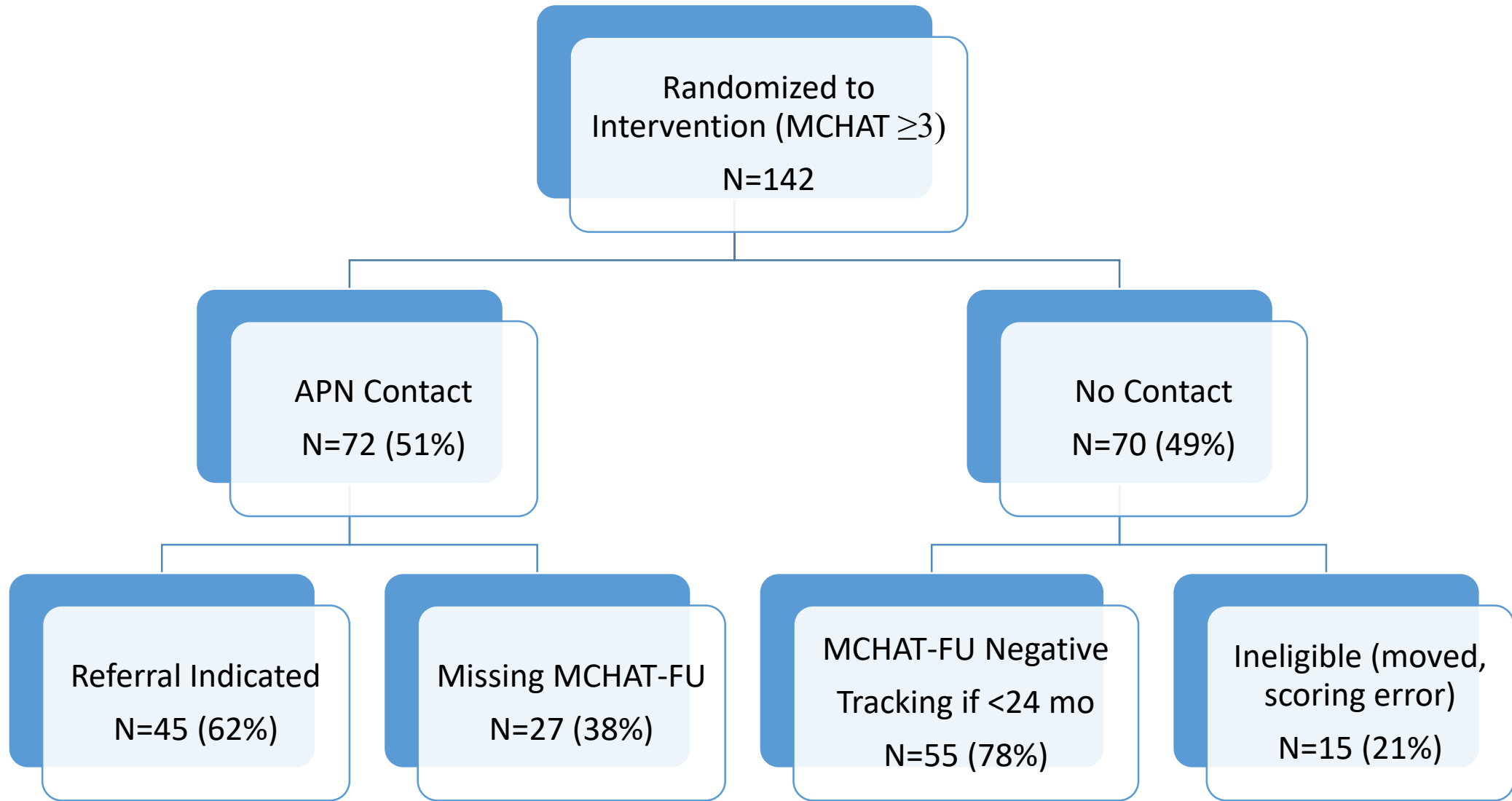
Demographic Characteristics by Study Group

	Intervention	Control
Language		
English	71%	69%
Spanish	21%	26%
Other	8%	4%
Insurance		
Medicaid	93%	95%
CHP+/DH Financial Assist. Program	2%	2%
Other (commercial, self-pay)	5%	4%

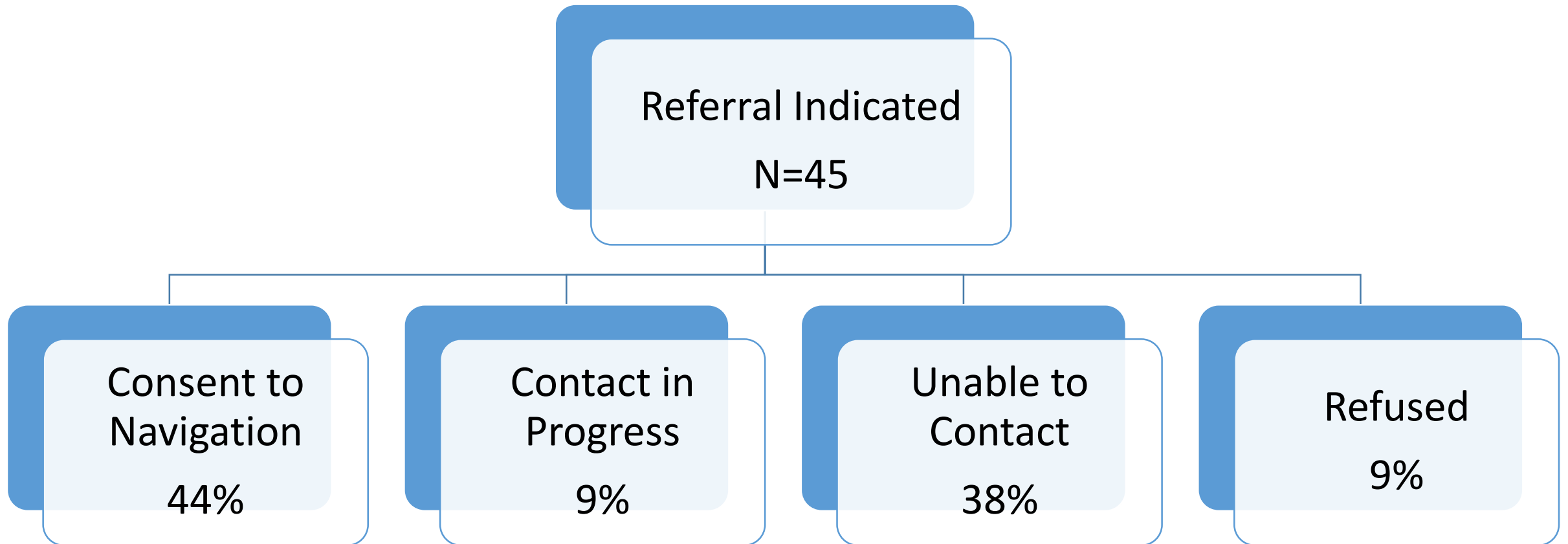
M-CHAT-R Score - Distribution by Study Group

	Intervention	Control
High Risk – Score 8 and above	10%	9%
Moderate Risk – Score 3-7	81%	82%
Score not recorded (“Fail”)	9%	10%

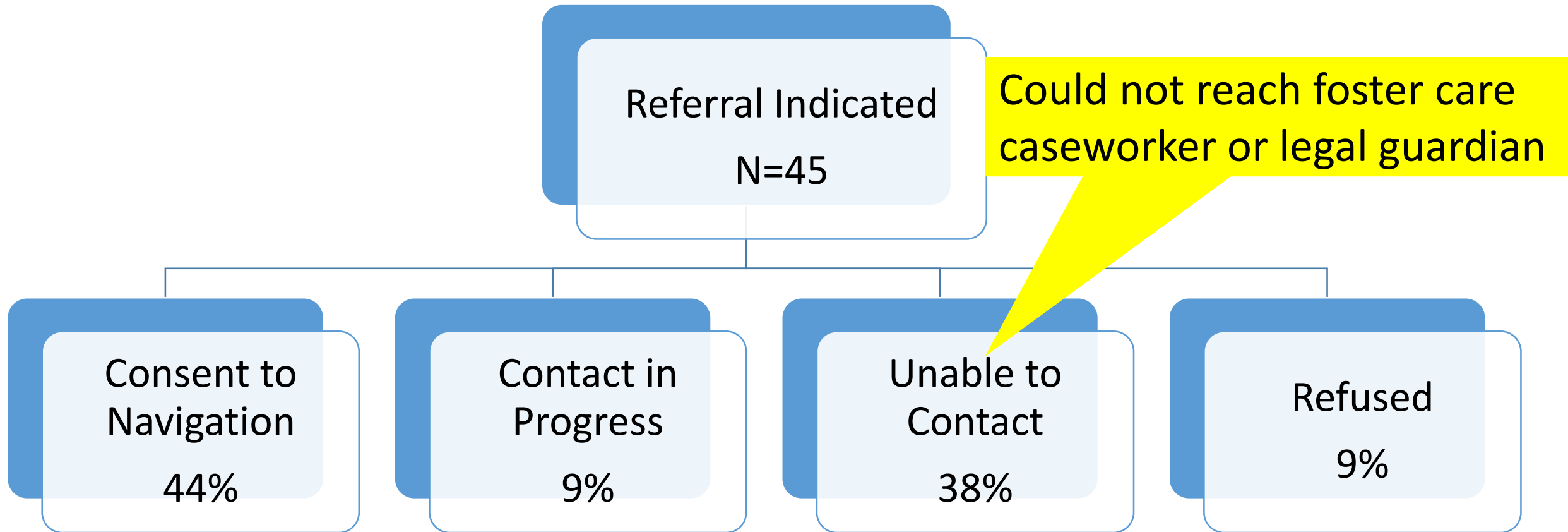
Eligibility for Autism Patient Navigator Contact among Children with Initial Positive Screen



Consent for Autism Patient Navigation among Children with M-CHAT Scores Indicating Referral



Consent for Autism Patient Navigation among Children with M-CHAT Scores Indicating Referral



Reach – How representative are families that engage with the APN?

- *Do families that engage with the APN differ from other intervention group families by child or family characteristics?*

Demographic Characteristics – Families Who Consented to Navigation versus All Other Intervention Families*

	Consented Families	Other Families
Age (mean)	21.2 mo	21.4 mo
Male	60%	63%
Insurance		
Medicaid	93%	93%
CHP+/DH Financial Assistance Program	7%	1%
Other (commercial, self-pay)	0%	6%

*Preliminary

Demographic Characteristics – Families Who Consented to Navigation versus All Other Intervention Families*

	Consented Families	Other Families
Hispanic Ethnicity	73%	59%
Race		
White Race	60%	45%
Black Race	13%	22%
Other Race	27%	33%
Language		
English	67%	71%
Spanish	33%	20%
Other	0%	9%

Demographic Characteristics – Families Who Consented to Navigation versus All Other Intervention Families*

	Consented Families	All Other Intervention Families
Hispanic Ethnicity	73%	22%
Race		
White Race	60%	22%
Black Race	13%	22%
Other Race	27%	33%
Language		
English	67%	71%
Spanish	33%	20%
Other	0%	9%

56% native Spanish speakers
44% most comfortable receiving new information in Spanish

Families Consenting to Navigation (to date)

- Families experienced an average of 4.5 different barriers to obtaining a diagnostic evaluation (range 0-12)
- Families diagnosed with ASD experienced an average of 3.0 different barriers to initiating services (range 0-8)

Preliminary Results: Barriers to Diagnostic Evaluation

Identified Barriers	%	Examples of Concerns
Scheduling Needs	81%	Difficulty scheduling early intervention (EI) appointment EI cancelled appointment Forgot or unaware of appointment Cannot take off work
Informational Needs	38%	Does not understand: purpose or results of M-CHAT, what autism is, purpose of referral, how to obtain evaluation, what EI is/does

Preliminary Results: Barriers to Diagnostic Evaluation

Identified Barriers	%	Examples of Concerns
Transportation Needs	31%	EI facility not accessible by bus, cost of bus fare No access to car/private transportation
Insurance Needs	25%	Unsure if Medicaid covers evaluation, needs help with Medicaid application, wants to change insurance
Medical Needs	25%	Child has other more pressing health concerns Other family members have healthcare needs

Preliminary Results: Barriers to Diagnostic Evaluation

Identified Barriers	%	Examples of Concerns
Beliefs and Attitudes about Health or Healthcare System	19%	Believes: child will improve on his own, pediatrician seemed unconcerned; autism not treatable, is stigmatized. Concerned evaluation will be inadequate due to race/ethnicity/citizenship
Physical Needs	19%	Needs: child care, housing, clothing, food
Language Needs	12%	Needs interpretation/translation

Preliminary Results: Barriers to Initiation and Engagement in Services after ASD Diagnosis

- Insurance/financial concerns (60%): inadequate insurance coverage, citizenship issues and difficulty paying bills
- Language and literacy needs (60%): need for interpretation, difficulty understanding materials due to high reading level, inability to read/write

System Barriers to Screening, Referral and Evaluation

- Clinics do not repeat screen at 24 months
- Clinics do not administer M-CHAT Follow-Up Interview
- Provider 'holds' after positive screening results
- No referral made despite positive results
- Referrals do not indicate need for ASD evaluation
- Foster care system

Autism Patient Navigation Activities

Barriers	Navigation / Assistance Provided
Scheduling Needs	Contacted EI on behalf of family to schedule / reschedule, worked with DH to resend referrals, made reminder calls to family, attended evals
Informational Needs	Educated families about autism, M-CHAT, evaluation, early intervention
Transportation Needs	Provided bus tokens, taxi vouchers, maps & parking information
Insurance/Financial Needs	Assisted with Medicaid application, provided info about coverage
Physical Needs	Provided clothing resources
Beliefs & Attitudes	Educated about ASD; attended evaluations with family
Language/Literacy Needs	Attended evaluations/meetings, assisted with interpretation/translation
Other	Provided emotional support after diagnosis; connect to support group; connected to services for 36+ months

Autism Patient Navigation Activities

- Healthcare System

- Trained clinic staff and providers on ASD, M-CHAT (19 training sessions + individual feedback)
- Gave feedback to providers & staff about need for M-CHAT-R Follow-up
- Educated providers about: 1) autism referral process and referral outcomes, 2) EI services and outcomes, 3) dual diagnoses
- Educated Denver Health Referral Coordinator re: ASD referrals
- Tracked intervention children screened at 18 mo to ensure 24 mo screen

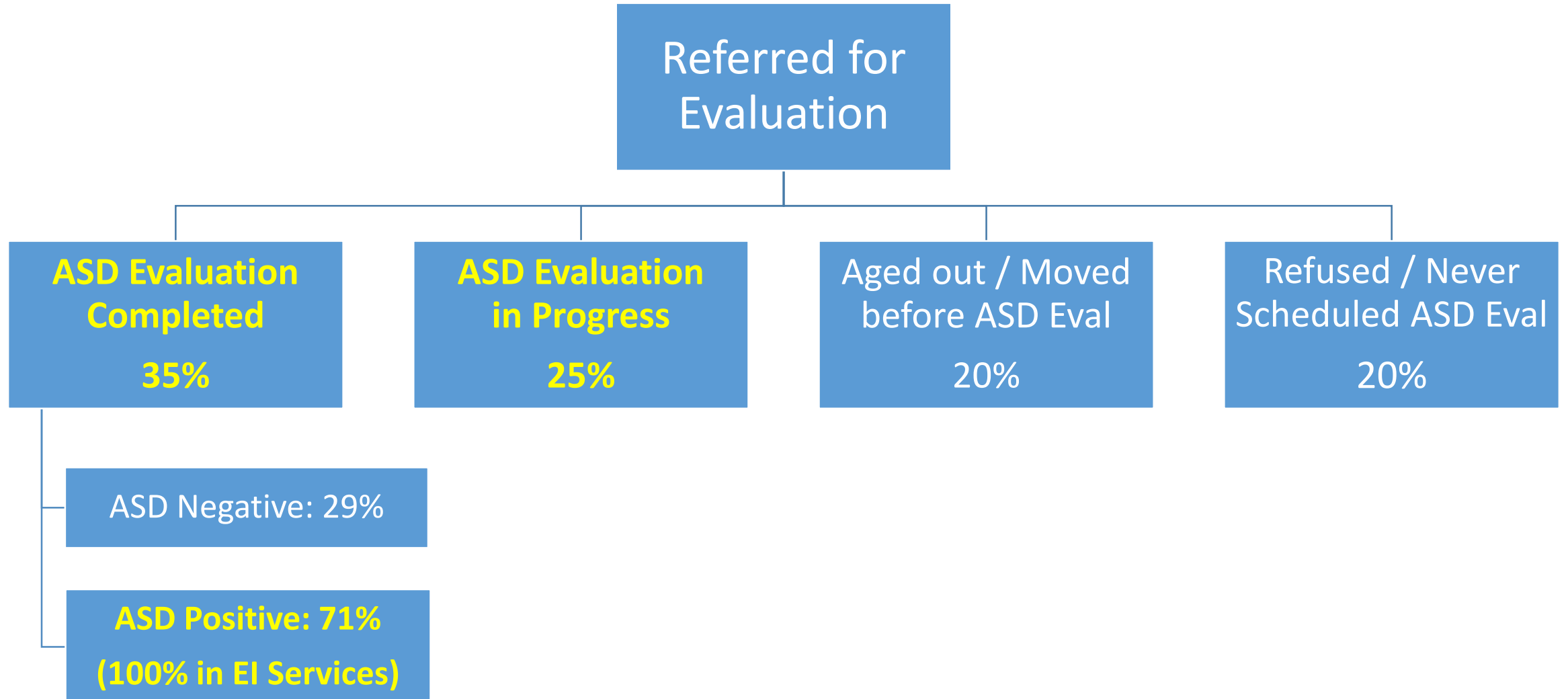
- Early Intervention System

- Established ongoing communication with RMHS
- Communicated with RMHS – DH providers not receiving feedback after referral

Case Study

- 34-year-old Hispanic, Spanish-speaking mother with two sons; younger son seen initially for 18 month well child visit
- Barriers to early diagnosis and services:
 - M-CHAT not completed at 18 month well visit
 - M-CHAT-R Follow-Up Interview not completed after positive MCHAT
 - Referral for ASD evaluation not made
 - Scheduling with Part C EI Services
 - Language barrier (Spanish-speaking only)
 - Informational needs
 - Psychosocial needs
 - Transportation needs

Preliminary Results: Families referred for evaluation who consented to navigation



Preliminary Conclusions:

- Low income, minority families whose children screen positive for ASD experience multiple different system and family barriers to accessing diagnostic evaluation and services
- Autism patient navigators can successfully reach and engage these families
- APN can provide a wide range of assistance to:
 - Help guide these families through and around these important barriers to timely diagnosis and treatment
 - Improve systems for ASD screening, referral, and evaluation
- Even with APN assistance, many children identified as at risk of ASD still do not obtain needed referral or ASD evaluation

Acknowledgement

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Thank you!