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

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Session Objectives

• Awareness of SaLSA trial, which is testing whether patient navigation improves families’ access to evaluation and treatment for autism spectrum disorder (ASD)

• Understanding of barriers experienced by families in obtaining early intervention evaluation and services, and how an Autism Patient Navigator can help address them
Screening for ASD

- 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**
- Among children who screen positive for ASD, many do not receive referrals for evaluation, undergo diagnostic evaluations or engage in treatment for ASD
Screening for ASD

- Minority, foreign born, less educated and low-income populations:
  - Receive referral, diagnosis and treatment later and less often
  - 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

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 delivery of preventive care in children and management of chronic conditions in adults

Not tested for improving early identification and treatment of ASD
Screening and Linkage to Services for Autism (SaLSA)

• SaLSA’s primary aim is to evaluate whether use of an Autism Patient Navigator (APN) improves families’ access to evaluation and treatment for ASD

• SaLSA also aims to:
  - Examine barriers to the successful engagement of families with young children in evaluation and treatment services for ASD
  - Identify ways patient navigation facilitates families access’ to evaluation and treatment services for young children at risk for ASD
  - Describe the feasibility of using APN in a safety net system
Setting: Denver Community Health Services

- >90% Medicaid / Medicaid eligible
- 74% Hispanic, 10% African American
Routine M-CHAT Screening

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

<table>
<thead>
<tr>
<th>0-2 Low Risk</th>
<th>3-7 Moderate Risk</th>
<th>8+ High Risk</th>
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<tbody>
<tr>
<td>• If &lt;24 months, repeat at 24-month well visit</td>
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<tr>
<td>• Otherwise, no further evaluation</td>
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<tr>
<td>• Implement M-CHAT-R Follow-Up Interview</td>
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<tr>
<td>• If positive, refer to EI program for ASD evaluation</td>
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Screening to Services Flow

Positive Screen → Referral for EI and ASD evaluation → EI evaluation → ASD evaluation → EI/ASD services
Study Population

Inclusion:
- Children aged 16-30 months, resident in Denver County
- Seen for well visit at a Denver Health primary care clinic
- Positive moderate/high risk M-CHAT-R (score ≥3)

Exclusion:
- Existing diagnosis of ASD
Study Design: Randomized Trial

Eligible M-CHAT-positive children randomly assigned to intervention group or control group

Autism Patient Navigator (APN) contacted each intervention group family whose child scored high enough to need referral for EI evaluation and offered navigation assistance
Outcomes

Receipt of diagnostic evaluation

Initiation of early intervention services

**Barriers to obtaining evaluation and services experienced by parents**

Parent and staff perceptions of patient navigator program
Data Collection & Analysis: Barriers

Semi-structured telephone interview with family to determine barriers and identify assistance needed:

- Intake interview at time of referral
- Second interview after Individualized Family Service Plan (IFSP)

APN coded parent responses directly onto data collection form

APN added any additional barriers identified during course of patient navigation to form

Unique barriers tabulated and categorized
Preliminary Results: Consent to Patient Navigation among Intervention Group Families

Eligible for APN Contact
N=45

- Consented: 44%
- Contact In Progress: 9%
- Refused: 9%
- Unable to Contact: 33%
- Not eligible: 4%
Preliminary Results – Consentling Families

93% Medicaid
75% Hispanic, 12% Black

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

Families experienced an average of 4.5 different barriers to obtaining a diagnostic evaluation (range 0-12)
Preliminary Results: Barriers to Diagnostic Evaluation

<table>
<thead>
<tr>
<th>Identified Barriers</th>
<th>%</th>
<th>Examples of Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling Needs</td>
<td>81%</td>
<td>Difficulty scheduling early intervention (EI) appointment</td>
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<tr>
<td></td>
<td></td>
<td>EI cancelled appointment</td>
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<tr>
<td></td>
<td></td>
<td>Forgot or unaware of appointment</td>
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<tr>
<td></td>
<td></td>
<td>Cannot take off work</td>
</tr>
<tr>
<td>Informational Needs</td>
<td>38%</td>
<td>Does not understand: purpose or results of M-CHAT, purpose of referral, how to obtain evaluation, what autism is, what EI is/does</td>
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### Preliminary Results: Barriers to Diagnostic Evaluation

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

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<tr>
<td>Beliefs and Attitudes about Health or</td>
<td>19%</td>
<td>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</td>
</tr>
<tr>
<td>Healthcare System</td>
<td></td>
<td></td>
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<tr>
<td>Physical Needs</td>
<td>19%</td>
<td>Needs: child care, housing, clothing, food</td>
</tr>
<tr>
<td>Language Needs</td>
<td>12%</td>
<td>Needs interpretation/translation</td>
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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
APN Activities – Scheduling Needs

- Contacted EI program on behalf of family to schedule / reschedule
- Worked with DH referral coordinator to send new referrals to EI
- Made reminder calls to family
- Gave families scheduling tracker
- Attended evaluations in family’s home
APN Activities – Informational Needs

• Educated families about autism
• Educated families about the purpose and results of the M-CHAT
• Educated families about the referral and testing process
• Educated families about early intervention services
APN Activities – Transportation Needs

• Provided maps and parking instructions
• Coordinated bus fare
• Provided taxi vouchers
• Communicated with taxi service on behalf of family
APN Activities – Insurance/Financial Needs

• Educated on insurance coverage for evaluations
• Assisted with Medicaid application
APN Activities – Physical Needs, Beliefs & Attitudes, Language & Other Needs

- Provided clothing resources
- Educated about ASD – chronic nature, benefits from EI services
- Attended meetings and evaluations with family
- Assisted with interpretation/translation
- Emotional support after diagnosis
APN Activities - System

• Group trainings (n=19) and individual feedback to clinic staff and providers on ASD and M-CHAT, including:
  ◦ Screening and autism referral process
  ◦ Completing and documenting M-CHAT and M-CHAT-R Follow-up
  ◦ ASD evaluation process through Early Intervention services (after referral)
  ◦ Early intervention services and outcomes
  ◦ Dual diagnoses (e.g., ASD and Down syndrome)

• Established ongoing communication with the birth to 3 years EI program, Rocky Mountain Humans Services (RMHS)
Conclusion

Low income families whose children screen positive for ASD experience multiple different barriers to accessing diagnostic evaluation and services, particularly related to scheduling and informational needs.

APN can provide a wide range of assistance to help guide these families through and around these important barriers to timely diagnosis and treatment.
Resources

• CDC: Learn the Signs. Act Early
  ◦ Autism Case Training: https://www.cdc.gov/ncbddd/actearly/act.html

• Autism Speaks
  ◦ Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. https://www.autismspeaks.org/
Resources

• El Grupo VIDA
  ◦ 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. http://www.elgrupovida.org/

• SaLSA Patient Navigation Resource Guide
  ◦ Copies available
Study Team

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El Grupo VIDA
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