SaLSA
Screening and Linkage to Services for Autism
Randomized Controlled Trial of Family Navigation
Carolyn DiGuiseppi, MD, MPH, PhD
February 20, 2020
Objectives

• Define family navigation and explain its potential role for young children with autism spectrum disorders
• Describe the results of the SaLSA (“Screening and Linkage to Services for Autism”) randomized trial among families seeking care at a community health center, including:
  • barriers families encountered
  • how family navigators assisted families
  • effects of navigation on referral and evaluation for ASD.
• 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 City & 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 behavioral observation, parent report, standardized testing
Welcome to El Grupo VIDA!
For people with disabilities or special needs who are Hispanic/Latino

[ About ] [ SPANISH ] [ Conference ] [ Events ] [ Services ] [ Contact ] [ Internships ]

"We are in this together!"

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.
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
- 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 families:
  - Less information about child development, ASD, how to obtain care
  - More problems accessing care due to financial, transportation, language, literacy or child care issues
  - More often report provider dismissal of parental concerns
  - Less trust of providers, healthcare and educational systems
  - Less satisfaction with EI evaluation and services

- Therefore: Receive referral, diagnosis and services less often and later
Family Navigation

- 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

Lurie Center, Autism Speaks
Potential Role of Autism Family Navigator (AFN)

- Educate families (and providers) about ASD, screening and diagnostic tests, early intervention (EI) system and services
- Assist with care coordination
- Coach families to self-advocate
- Offer psychosocial support
- Assist with practical barriers
Aim 1: Examine the effect of autism family navigation on referral, ASD diagnostic evaluation, and linkage to services in a largely minority, disadvantaged population.

Aim 2: Examine the reach and implementation of autism family navigation in this setting.
Methods
Setting: Denver Community Health Services

Network of community and school-based health centers located throughout Denver that provide primary care

Affordable healthcare for low income populations

Patient population: >90% low income, 84% minority
Routine ASD Screening at Denver Health

- ASD Screen at 18- and 24-month well child visits in primary care clinics
- Modified Checklist for Autism in Toddlers-Revised with Follow-Up (MCHAT-R/F): two-stage 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>
</tr>
</thead>
<tbody>
<tr>
<td>- If &lt;24 months, repeat at 24-month well visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Otherwise, no further evaluation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Implement MCHAT-R Follow-Up</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- If positive (&gt;1), referred for ASD evaluation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Referred for ASD evaluation</td>
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</table>
## Study Population

<table>
<thead>
<tr>
<th>Inclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Children aged 16-30 months</td>
</tr>
<tr>
<td>• Seen for well visit at DH primary care clinics</td>
</tr>
<tr>
<td>• Positive <em>initial</em> MCHAT-R (score ≥3; moderate or high risk) recorded in the Electronic Health Record</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Existing ASD diagnosis</td>
</tr>
<tr>
<td>• Not resident of Denver City &amp; County</td>
</tr>
</tbody>
</table>
Screening to Services Flow

Positive MCHAT-R → Follow-Up (if indicated) → Referral for evaluation → Child Find evaluation → IFSP and EI Services → ASD evaluation

Referral for evaluation → Follow-Up (if indicated)

Child Find evaluation → IFSP and EI Services

IFSP and EI Services → ASD evaluation

ASD evaluation → Positive MCHAT-R
Screening to Services Flow

Barriers

Positive MCHAT-R → Follow-Up (if indicated) → Referral for EI evaluation → Child Find evaluation → IFSP and EI Services → ASD evaluation

ASD evaluation → IFSP and EI Services → Child Find evaluation → Referral for EI evaluation → Follow-Up (if indicated) → Positive MCHAT-R

Screening to Services Flow
Autism Family Navigators

• Two bilingual, Latina staff members housed within Denver Health

• Extensive training
  • **Standardized training** (Patient Navigator Training Collaborative) including modeling, practice and feedback
    • Communication and problem-solving skills
    • Coordinating care among providers, agencies and organizations
    • Providing support, education, and coaching for caregivers
    • Finding and evaluating patient resources
  • **Project-specific training**
    • ASD presentation, screening, diagnosis, treatment and prognosis
    • Orientation to Part C Early Intervention services and RMHS
Study Design: Randomized Controlled Trial

Age 16-30 months
MCHAT ≥3 in EHR

Randomization

Intervention
AFN reviews EHR

Follow-Up < 2 or MCHAT 0-2 (after EHR review)
Navigation Not Offered

Referral Needed (MCHAT 8+ or MCHAT 3-7 & F/U ≥2)
AFN Contact: Offer Navigation
MCHAT 3-7 & Follow-Up not done
AFN Contact: Assist to complete F/U

Control

If F/U < 2
If F/U ≥2
Autism Patient Navigator Procedures

• If referral for EI evaluation *made or needed*:
  • Telephone family, obtain consent and interview about barriers
  • If indicated referral for ASD evaluation not made, contact provider / staff to ensure appropriate referral or coach family to do so
  • Provide family with assistance, resources, and education about ASD and EI
  • Maintain ongoing communication and support
Primary Outcomes (Aim 1)

Family Navigation

MCHAT-R Follow-up ➔ Referral for EI evaluation ➔ Child Find Evaluation for EI service eligibility ➔ ASD evaluation ➔ IFSP, Referral for EI/ASD services
Secondary Outcomes

• Barriers experienced by families
• Implementation of navigation
Data Sources

- Linked electronic health and early intervention services records to evaluate primary outcomes
- Standardized semi-structured interviews with intervention group parents at time of consent to identify barriers
- Navigator records – contacts and activities
Analysis Plan

- Primary outcomes compared between randomized groups based on intention-to-treat, using chi-squared tests
- Effects of the intervention estimated using log-binomial models
- Barriers experienced by families consenting to navigation categorized and tabulated
- AFN navigation activities enumerated, categorized and tabulated
Results
Children with Initial MCHAT ≥3
Randomized to Study Groups

Randomized
N=275

Intervention Group
N=142 (52%)

Control Group
N=133 (48%)
Demographic Characteristics by Study Group

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>21 mo</td>
<td>21 mo</td>
</tr>
<tr>
<td>Male</td>
<td>61%</td>
<td>64%</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White Race</td>
<td>56%</td>
<td>57%</td>
</tr>
<tr>
<td>Black Race</td>
<td>20%</td>
<td>17%</td>
</tr>
<tr>
<td>Other Race</td>
<td>24%</td>
<td>26%</td>
</tr>
<tr>
<td>Hispanic Ethnicity</td>
<td>62%</td>
<td>59%</td>
</tr>
</tbody>
</table>
## Demographic Characteristics by Study Group

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
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</thead>
<tbody>
<tr>
<td>Language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>70%</td>
<td>69%</td>
</tr>
<tr>
<td>Spanish</td>
<td>23%</td>
<td>26%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
<td>5%</td>
</tr>
<tr>
<td>Medicaid Insurance</td>
<td>92%</td>
<td>93%</td>
</tr>
<tr>
<td>At Least One Complex Chronic Condition</td>
<td>8%</td>
<td>11%</td>
</tr>
<tr>
<td>Household Income Below Federal Poverty Level</td>
<td>77%</td>
<td>73%</td>
</tr>
<tr>
<td>Risk Level</td>
<td>Intervention</td>
<td>Control</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>--------------</td>
<td>---------</td>
</tr>
<tr>
<td>High Risk – Score 8 and above</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Moderate Risk – Score 3-7</td>
<td>82%</td>
<td>83%</td>
</tr>
<tr>
<td>“Fail” (Score not recorded)</td>
<td>10%</td>
<td>8%</td>
</tr>
</tbody>
</table>
Children Randomized to Intervention Group

Intervention Group (MCHAT ≥3)  
N=142

- Navigation Not Needed  
  N=68 (48%)

- MCHAT Follow-Up Not Done  
  N=22 (15%)

- Not Eligible (Age, Residence)  
  N=6 (4%)

- Potentially Eligible for Navigation  
  N=46 (32%)
Consent for Autism Family Navigation among Children Needing Referral for ASD Evaluation

Potentially Eligible for Navigation
N=46

Consent to Navigation
N=22 (48%)

Refused
N=6 (13%)

Unable to Contact
N=14 (30%)

Foster Care, Contact Refused
N=4 (9%)
Children whose Families Consented to Navigation Versus All Other Intervention Group Families

<table>
<thead>
<tr>
<th></th>
<th>Consented Families</th>
<th>All Other Intervention Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>21.2 mo</td>
<td>21.4 mo</td>
</tr>
<tr>
<td>Male</td>
<td>64%</td>
<td>60%</td>
</tr>
<tr>
<td>Medicaid Insurance</td>
<td>95%</td>
<td>92%</td>
</tr>
<tr>
<td>At least one chronic medical condition</td>
<td>9%</td>
<td>8%</td>
</tr>
</tbody>
</table>
Children whose Families Consented to Navigation Versus All Other Intervention Families

<table>
<thead>
<tr>
<th>Child Characteristics</th>
<th>Consented Families</th>
<th>All Other Intervention Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic Ethnicity</td>
<td>77%</td>
<td>59%</td>
</tr>
<tr>
<td>White Race</td>
<td>82%</td>
<td>51%</td>
</tr>
<tr>
<td>Spanish Language</td>
<td>41%</td>
<td>19%</td>
</tr>
<tr>
<td>MCHAT-R - High Risk (8+)</td>
<td>27%</td>
<td>5%</td>
</tr>
</tbody>
</table>
Families Consenting to Navigation: Interview

<table>
<thead>
<tr>
<th>Maternal &amp; Household Characteristics</th>
<th>N=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic Ethnicity</td>
<td>82%</td>
</tr>
<tr>
<td>Native Language – Spanish</td>
<td>64%</td>
</tr>
<tr>
<td>Less than High School Diploma</td>
<td>57%</td>
</tr>
<tr>
<td>Annual Household Income &lt;$30,000</td>
<td>71%</td>
</tr>
</tbody>
</table>
Families Consenting to Navigation: Interview

<table>
<thead>
<tr>
<th>Maternal &amp; Household Characteristics</th>
<th>N=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred Language for New Information – Spanish</td>
<td>45%</td>
</tr>
<tr>
<td>Preferred Method for Learning about Child’s Health</td>
<td></td>
</tr>
<tr>
<td>Listening / Person-to-Person</td>
<td>76%</td>
</tr>
<tr>
<td>Watching Videos</td>
<td>62%</td>
</tr>
<tr>
<td>Reading Written Materials</td>
<td>57%</td>
</tr>
<tr>
<td>Internet / Websites</td>
<td>29%</td>
</tr>
</tbody>
</table>
Parent-reported barriers to obtaining ASD evaluation after positive screen: **Pragmatic**

<table>
<thead>
<tr>
<th>Identified Barriers</th>
<th>%</th>
<th>Examples of Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling Needs</td>
<td>68%</td>
<td>Difficulty scheduling early intervention (EI) appointment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>EI cancelled appointment; forgot or unaware of appointment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cannot take off work</td>
</tr>
<tr>
<td>Transportation Needs</td>
<td>23%</td>
<td>Facility not accessible by bus, cost of bus or taxi fare</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No access to car/private transportation</td>
</tr>
<tr>
<td>Insurance Needs</td>
<td>23%</td>
<td>Unsure if Medicaid covers evaluation, needs help with Medicaid application, wants to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>change insurance</td>
</tr>
<tr>
<td>Medical Needs</td>
<td>18%</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>Physical Needs</td>
<td>18%</td>
<td>Needs: child care, housing, clothing, food</td>
</tr>
</tbody>
</table>
Parent-reported barriers to obtaining ASD evaluation after positive screen: **Informational**

<table>
<thead>
<tr>
<th>Identified Barriers</th>
<th>%</th>
<th>Examples of Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Needs</td>
<td>46%</td>
<td>Does not understand: purpose or results of MCHAT, what autism is, purpose of referral, how to obtain evaluation, what EI is/does</td>
</tr>
<tr>
<td>Language Needs</td>
<td>18%</td>
<td>Needs interpretation/translation</td>
</tr>
</tbody>
</table>
Parent-reported barriers to obtaining ASD evaluation after positive screen: **Beliefs and Attitudes**

<table>
<thead>
<tr>
<th>Identified Barriers</th>
<th>%</th>
<th>Examples of Concerns</th>
</tr>
</thead>
</table>
| Beliefs and Attitudes about Health or Healthcare System | 32% | Believes child will improve on his own  
Pediatrician seemed unconcerned  
Believes autism not treatable  
Stigmatization  
Evaluation will be inadequate due to race/ethnicity/citizenship |
Other barriers

**Residence or Contact Information Changes (27%)**
- Phone disconnected, moved out of county

**System Barriers (64%)**
- MCHAT Follow-Up indicated, not administered
- No referral after positive results
- Referrals do not indicate need for ASD evaluation
- Provider “hold” on referral after positive screen
- No screen performed at 24 months after 18-month screen
- Turnover of staff trained to screen with MCHAT-R
- Waiting list for ASD evaluations at EI agency
Barriers to obtaining ASD evaluation after positive screen

Families reported a median of 4 different barriers (range 1-13), and median of 2.5 different types of barriers (range 1-8), to obtaining an evaluation.

50% of families experienced 5 or more barriers to obtaining an ASD evaluation.
## Autism Family Navigation Activities for Families

<table>
<thead>
<tr>
<th>Activity</th>
<th>Examples of Navigation / Assistance Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Coordination</td>
<td>Ensured ASD referral; contacted EI to schedule evaluation; reminded families of upcoming visits</td>
</tr>
<tr>
<td>Education</td>
<td>Educated families about autism, evaluation, early intervention; explained evaluation results</td>
</tr>
<tr>
<td>Social/Emotional Support</td>
<td>Attended evaluations with family</td>
</tr>
<tr>
<td>Advocacy on Family’s Behalf</td>
<td>Communicated with DH provider re: ASD referral</td>
</tr>
<tr>
<td>Empowerment of Family</td>
<td>Coached families to self-advocate to obtain referral</td>
</tr>
<tr>
<td>Transportation resources</td>
<td>Arranged taxi fare</td>
</tr>
<tr>
<td>Interpretation / translation</td>
<td>Translated written evaluation results</td>
</tr>
<tr>
<td>Insurance Resources</td>
<td>Assisted with Medicaid application</td>
</tr>
</tbody>
</table>
Family Navigator Activities

- Care coordination
- Education
- Social/emotional support
- Advocacy on family's behalf
- Empowerment of family
- Transportation resources
- Interpretation/translation
- Insurance resources
- Physical resources
Autism Family Navigation Activities: System

Healthcare System
- Training sessions for staff, providers
- Individual staff observation & feedback
- Educated Referral Coordinator re: ASD referrals
- Educational bulletins about autism referral process and referral outcomes, EI services and outcomes
- Tracking and reminders to ensure screens at 24 months and after “holds” were completed

Early Intervention System
- Ongoing communication with RMHS to coordinate evaluation, services

Community
- Multiple community events to raise awareness about ASD, screening and evaluation, EI services
Results: Primary Outcomes (Intention to Treat)

- Completed M-CHAT-R/F: 50% Intervention, 40% Control
- Referred for Evaluation: 40% Intervention, 30% Control
- Evaluated for EI Eligibility: 30% Intervention, 20% Control
- Referred for EI Services: 20% Intervention, 15% Control
- Evaluated for ASD: 5% Intervention, 10% Control

* p=0.04
* p=0.02
### ASD Evaluation and Diagnosis (Intention to Treat)

<table>
<thead>
<tr>
<th></th>
<th>Intervention (n=142)</th>
<th>Control (N=133)</th>
<th>Risk Ratio (95% CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received Comprehensive ASD Evaluation</td>
<td>15 (11%)</td>
<td>5 (4%)</td>
<td>2.81 (1.03, 7.52)</td>
<td>0.04</td>
</tr>
<tr>
<td>Received ASD Diagnosis</td>
<td>12 (8%)</td>
<td>5 (4%)</td>
<td>2.25 (0.81, 6.21)</td>
<td>0.12</td>
</tr>
</tbody>
</table>
Families Receiving Autism Family Navigation

100% Referred to EI for Evaluation

73% Received EI Evaluation

46% Completed ASD Evaluation
23% Scheduled or on Wait List

36% Diagnosed with ASD

36% Initiated EI Services
Context: Other Trials

Feinberg et al (2016)

- 40 minority or disadvantaged children aged 15 months - 6 years referred for ASD evaluation
- Compared navigation to no navigation
- 80% of families reported five or more barriers to evaluation (most commonly pragmatic issues, informational needs)
- Children receiving navigation were 3 times as likely to complete a diagnostic assessment within one year, and twice as likely to be diagnosed with ASD

Roth et al (2016)

- 39 children aged <48 months, recently diagnosed with ASD; half Medicaid-eligible.
- Compared navigation implemented 1 week versus 3 months after diagnosis
- Early navigation significantly increased scheduling and completion of appointments for recommended services
Conclusions
• Disadvantaged families whose children screen positive for ASD experience multiple barriers to accessing diagnostic evaluation and services

• AFNs can provide a wide range of assistance, particularly care coordination and education

• Intervention children were 25% more likely to have completed the two-step MCHAT-R/F

• Intervention children ~ three times as likely to complete ASD evaluations compared to controls

• Half of families potentially eligible for navigation refused or could not be contacted

• Latina, Spanish-speaking mothers were more likely to engage with AFNs
Conclusions:

• Autism family navigation implemented in an urban, community health center system is feasible and effective in increasing ASD evaluation of at-risk toddlers

• Autism family navigation is effective in improving the quality of ASD screening, which may reduce unnecessary referrals.

• Low income, minority families hesitant to respond to offers of assistance from AFNs, reducing potential impact of an AFN program

• Families may be more likely to engage with AFNs who represent their own cultural and linguistic characteristics
Recommendations for Implementation

• Embed AFN program within the clinical setting so that initial contacts are made in person and based on provider referrals
• Enhance visibility and understanding of the AFN role among clinicians
• Ensure AFN develops and maintains relationships with primary care and EI staff and understands their objectives, protocols and processes
• Conduct community outreach and develop partnerships with community organizations to reduce stigma, enhance trust
Study Team

• University of Colorado Anschutz Medical Campus
  • Carolyn DiGuiseppi, MD, PhD (PI)
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• Rocky Mountain Human Services
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  • Beth Scully
  • Lindsey Krings

• Denver Health Medical Center
  • Margaret Tomcho, MD, MPH, MBA
  • Simon Hambidge, MD, PhD
  • Silvia Gutiérrez-Raghunath (Navigator)
  • Rosse Rodriguez-Perez MD (Navigator)
  • Kristin Breslow, MPH, Analyst
  • Anita Roberts, RN
  • Sarah Leslie, MPH
  • Sarah Sabolot

• El Grupo VIDA
  • Jeanette Cordova (now at Bright Futures LLC)
Acknowledgements

• This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number R40MC27702, and the R40 Maternal and Child Health Field-initiated Innovative Research Studies Program. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

• Additional support was provided by NIH/NCRR Colorado CTSI Grant Number UL1 RR025780.
Thank you!