Background

“As pediatric primary health care providers increase appropriate developmental screening and early identification of developmental delays in young children, the weak linkages among providers of services to children and families become increasingly apparent. Young children often fall through the cracks between pediatric primary health care providers and providers of mental health, early intervention, child welfare, and education services.”

- National Academy for State Health Policy, 2009

As a result of observing this gap between pediatric primary care providers (PPCPs) and other providers of early childhood services, the Oregon Assuring Better Child and Health Development (ABCD) Screening Initiative developed recommended screening and referral practice guidelines in primary care settings. Screening and referral practices in primary care settings have been supported by the Screening Tool & Referral Training (START) program of the Oregon Pediatric Society, the local chapter of the American Academy of Pediatrics, to assist PPCPs in adopting screening and referral practices consistent with ABCD guidelines.

The Individuals with Disabilities Education Act (IDEA) requires each state to provide early intervention and early childhood special education services at no cost to all qualifying children. The Oregon Department of Education contracts with agencies to provide a statewide system of free services for young children with developmental delays and disabilities.

Results

Child Characteristics

All children referred to MECP between July 1, 2013 and June 30, 2014 were included in the analysis, representing 2,418 children and a total of 2,716 referrals.

The majority of children (72%) were identified as speaking English as their primary language at home, followed by Spanish-speakers (19%), and all other languages combined (9%).

The majority of children (56%) were most recently referred to Early Intervention (EI, serving 0-3 year-olds), with 44% referred to Early Childhood Special Education (ECSE, serving 4-5 year-olds).
Table 1 shows similar rates among race/ethnic groups of children referred to MECP, compared to the County overall. Nonetheless, Asian, American Indian, and Multiracial children are slightly under-represented in MECP referrals, while White, Black, and Latino children are slightly overrepresented.

Table 1. Child Race/ Ethnicity Characteristics

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>MECP-Referral Children (N=2,306)</th>
<th>Multnomah County 0-4 y/o (N=46,298)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>79%</td>
<td>73%</td>
</tr>
<tr>
<td>Black</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Asian</td>
<td>4%</td>
<td>6%</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Native American</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>7%</td>
<td>10%</td>
</tr>
<tr>
<td>Latino1</td>
<td>24%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Overall, the mean child age at first referral was 28.6 months, ranging from 25.4 months for American Indian children, to 30.8 months for Black children. Although the average age of Black children at first referral was slightly older than the average for all children referred to MECP, Black children are referred more often.

Although 71% of all children in the time period had only one referral to MECP, this was true for only 55% of Black children and for 59% of American Indian children. In other words, 45% of Black children and 41% of American Indian children had at least 2 referrals in their history, compared to 29% of children overall.

Referral Source

MECP tracks the source of the child’s referral for further evaluation and assessment. For the purposes of this report, referral sources are grouped into four categories: 1) Family, which includes the child’s parents, caregivers, and extended kin; 2) Physician/Clinic, which includes health care providers in primary care, community health, and hospital settings; 3) early care and education (ECE) providers, which includes child care, preschool, and Head Start; and 4) All Others, which includes children referred from a variety of other programs including home visiting, child welfare, and other early intervention programs.

As shown in Table 2, physicians account for the highest rate of referrals of young children to EI (42%), while family members account for the highest rate of referrals of older children (47%), followed by ECE Providers (27%). This is expected, based on where children are typically and regularly seen by providers in the 0-3 and 4-5 year-old ranges.

Table 2. Referral Program by Source

<table>
<thead>
<tr>
<th>Referrals to EI (0-3 y/o) (N=1,482)</th>
<th>Referrals to ECSE (4-5 y/o) (N=1,118)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>36%</td>
</tr>
<tr>
<td>Physician</td>
<td>42%</td>
</tr>
<tr>
<td>ECE Providers</td>
<td>7%</td>
</tr>
<tr>
<td>All Others</td>
<td>13%</td>
</tr>
</tbody>
</table>

Referral Outcomes

Once referred, MECP has a federally-mandated 45-day window in which to complete further evaluation for a child’s eligibility for EI services. There are five possible referral outcomes for the child:

1) **Evaluated & Served**: The child is evaluated, is eligible for, and engages in, MECP services.

2) **Evaluated & Did Not Qualify (DNQ)**: The child is evaluated, but found not eligible for, MECP services. This may result in additional referrals to other community services for the family, and the MECP referral is closed.

3) **No Concerns (NC)**: During the process to schedule an evaluation for the child within the 45-day time frame, the family expresses no further concerns, and the referral is closed without an evaluation.

4) **Parent Delay (PD)**: During the process to schedule an evaluation for the child within the 45-day time frame, the family expresses extenuating circumstances that prevents them from completing an evaluation, and the referral is closed without an evaluation. This may include lengthy travel time to visit extended family out-of-country, or loss of housing, for example.

5) **Could Not Locate (CNL)**: During the process to schedule an evaluation for the child in the required time frames (45 calendar days for EI, or 60 school days from signed consent date for evaluation for ECSE), the family is unreachable after multiple and varied attempts to contact, and the referral is closed without an evaluation.

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2 These race/ethnicity categories are those defined in the dataset by Oregon Department of Education.

3 112 children were missing race/ethnicity in MECP data.

4 “Latino” represents children of any race.

5 116 referrals were missing race/ethnicity in MECP data.
The rates of referrals resulting in each of these outcome categories vary across referral source and race/ethnicity of the child. For the purposes of this report, referral outcomes have been collapsed into three categories: 1) **Evaluated**, which includes both children who were evaluated and found eligible or ineligible for services; 2) **Not Evaluated**, which combines the categories of No Concerns and Parent Delay – where parent contact was made by MECP but the child did not complete an evaluation; and 3) **Could Not Locate**, which represents families who were unreachable or did not respond to multiple attempts to complete an evaluation.

Comparisons in Figures 1 through 4 show referral source and outcomes for three race/ethnic groups of children: White, Black, and Latino. These groups were sufficiently large to make comparisons while maintaining confidentiality of families.

**Figure 1. Referral Source Family:**
Referral Outcome by Race/Ethnicity of Child

The light grey bars in Figures 1 through 4 show Black children consistently reaching evaluation at lower rates, compared to White and Latino children, regardless of referral source. The dark green bars in each figure show the higher rates of Black and Latino children in families unable to be located, compared to White children.

Surprisingly, 41% of Black children referred to MECP by someone in their own family, did not make it to evaluation for eligibility due to the family ultimately expressing no concern, expressing need for a delay, or being unreachable.

Referrals to MECP from physicians resulted in the lowest evaluation rates across child race/ethnic groups and resulted in the highest rates of families who either declined evaluation or were unable to be located for both White and Black children.
Discussion

Areas of Strength

Young Child Wellness Council (YCWC) members, PPCPs, and developmental pediatricians (DPs), who participated in data conversations, described strengths in the early intervention and identification system:

- The developmental screening training module offered through the START program and the ABCD initiative have been effective in promoting practice change related to regular developmental screening within Multnomah County pediatric health care settings.

- The total number of referrals to MECP by physicians continues to increase over time. From October 2012 through June 2013, 159 referrals to MECP came from this referral source. For the same time period in 2014-2015, nearly twice as many (n=336) referrals to MECP came from physicians.

- The development and use of a Universal Referral Form has improved communication between referring physicians and MECP on the results of developmental screenings and outcome of referrals.

- There is agreement that health care providers seek to improve universal screening and referral practices in order to continue to facilitate access to early intervention services for families at the earliest possible age, in culturally-relevant and responsive ways.

Challenges

Reviewing the MECP data by referral source and race/ethnicity raised additional questions and concerns about the effectiveness and cultural responsiveness of referrals for Black children overall, and from physician sources in particular for children of all race/ethnic groups.

- PPCPs and DPs voiced a need for additional tools or training to talk with families in culturally-relevant and responsive ways about the purpose of screening and referral, what families can expect in the referral and evaluation process, and what services can be available to families if their child is eligible.

- Providers suspected that stronger, positive relationships with families would contribute to families understanding and trusting the referral and evaluation process, but providers also were frustrated that building relationships with families in short, periodic well-child visits was difficult.

- Providers acknowledged that some families, and especially for families of color and immigrant families, there is a stigma attached to early intervention and special education services, and that this label can carry forward in the K-12 education system.

- Providers noted that some families may face significant barriers that interfere with their ability to get their child evaluated, e.g., transportation, child care and work demands, or unstable housing.

- Despite improvements to the communication process between MECP and PPCPs on the outcome of a referral to MECP, there is a recognition that PPCPs still too often do not know whether a family followed-through with an evaluation.

- Providers were unclear how the EI/ECSE and developmental pediatrician (DP) systems work for families, and how the pathways to these services exist for some families but not for others, i.e., more affluent families may be able to access DP care through private insurance, in contrast to lower-income families who may not be able to access DP care; but the types of delays or challenges covered by DPs may be different than those that can be supported through EI/ECSE.
Recommendations

Training for Providers

Stemming from conversations with YCWC members, PPCPs, and DPs, recommendations were made to strengthen training for PPCPs in a variety of ways:

- Modify the existing START training modules on developmental screenings to incorporate data on the high number of families, and in particular, Black families who do not make it to an MECP evaluation after a physician referral. In the training, emphasize the importance of encouraging PPCPs to take a more active role in following-up with families to follow-through after a referral.

- Continue to emphasize the importance of knowing strategies to build positive, trusting relationships between PPCPs and families during short, periodic well-child visits.

- Consider ongoing training for providers to understand the impact of trauma on children and families, including understanding the experiences of racism among families of color, and how to build relationships through a trauma-informed lens.

- Continue to provide opportunities and supports for PPCPs, DPs and MECP understand how EI/ECSE and DP systems can best work in concert to meet families’ needs.

Strategies for Communicating with Families

In order for families to better understand the purpose and process of screening, referral, and evaluation, recommendations include:

- PPCPs to build more culturally-responsive and –inclusive language, including trauma-informed language, in describing the purpose, importance, and consequences of developmental screenings with families. One example includes avoiding the use of developmental “concerns” with Latino/Spanish-speaking families, who may not interpret “concern” as cause for follow-up on a referral.

- LAUNCH to support the development of messaging tools for PPCPs to use with families that describe the referral and evaluation process, for routes both to EI/ECSE, and to DPs. These should also be translated into multiple languages and interpreted for cross-cultural relevance.

- PPCPs to consider describing referral and evaluation to MECP in a positive way to promote school readiness and the child’s full potential, rather than being a negative label of the child being developmentally deficient. However, PPCPs should continue to be mindful of families concerns about stigmatization, or negative experiences that families may have previously had, in terms of accessing supports.

- Based on learnings from an ABCD study, PPCPs to routinely follow-up with referred families within 72 hours to reinforce the importance of families to follow-through with a referral to MECP.

Building Systemic Supports

In addition to training for providers and tools to assist PPCPs communicate with families, system-level recommendations include:

- Continue to increase the use of the Universal Referral Form between and MECP, and for PPCPs and MECP to continue to work together on a continuous improvement process focused on increasing feedback provided by MECP to PPCPs with the outcome of referrals.

- Support and evaluate MECP’s efforts to hire and pilot use of a Community Health Worker to assist families from specific cultural communities to navigate the screening, referral, evaluation, and EI/ECSE service system.

- Consider other innovation pilot studies to help PPCPs and MECP address socioeconomic barriers that prevent families from following-through on a referral.

- Consider creating opportunities for families to share their experiences with MECP, including those with children who were referred and not evaluated, as well as with those whose children were referred and evaluated, in order to more fully understand their recommendations to make the referral system more culturally responsive and trauma-informed.
• Similarly, consider creating opportunities for early childhood service providers, including child care providers and home visitors, to share their experiences working with families to refer children to MECP for evaluation.

• Finally, further investigate and understand the circumstances in which families would access and benefit from MECP versus DP services, as well as when these services might best be utilized in tandem.

In summary, although 63% of all children who are referred to MECP from all sources complete an evaluation and are either found eligible or ineligible for services, this rate varies by race/ethnicity of the child and be referral source. Although there is a wide range of challenges that families may face when their child is referred to EI/ECSE, including culturally-specific and socioeconomic barriers, Multnomah Project LAUNCH gave providers an opportunity to learn more about post-referral outcomes to MECP in order to strategize solutions to better serve all children and families in Multnomah County.

References


Recommended Citation


Endnote

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